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QUALITY OF LIFE IN NURSING HOMES

COMPLETED

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

APRIL 28, 1986, NEW YORK, NY

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QUALITY OF LIFE IN NURSING HOMES

MONDAY, APRIL 28, 1986

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
SUBCOMMITTEE ON HUMAN SERVICES,
New York, NY.

The subcommittee met, pursuant to notice, at 1:30 p.m., at One Police Plaza, New York, NY, the Hon. Mario Biaggi (chairman of the subcommittee) presiding.

Members present: Representatives Biaggi and Manton.

Staff present: Bob Blancato, staff director, and Moya Benoit, research assistant.

OPENING STATEMENT OF CHAIRMAN MARIO BIAGGI

Mr. BIAGGI. The hearing is called to order. And I welcome all my good senior friends and their friends on this occasion. This is a hearing by the Subcommittee on Human Services, which I chair. We are accompanied by my colleague, Congressman Thomas Manton, who is on the House Select Committee on Aging.

When he first came to the Congress, he came to me and said, "Mario, one committee I must serve on is on the Aging Committee because my mother is getting elderly, and I want to make sure that we take care of her and all of her friends." So, we managed to arrange that, and ever since he has been on the committee he has been a good, loyal, and hard-working member.

We have a young lady on my left who everyone knows. She is known nationally and internationally because there is only one Commissioner Janet Sainer, who has been so great in the work for the elderly in our city. This is one lady that will never be forgotten.

I would like to tell you that as we meet here today the House of Representatives is voting on a bill, House Joint Resolution 533, which designates April 28 of this year as National Nursing Home Residents Day. That was passed last week by the Senate. Again, the reason we do that is to focus once again on the nursing homes in our country.

Now, we know about nursing homes. We have been involved with them for some period of time. On the most part they are good. On the most part, but when they are bad, we find them very, very bad. And those are the conditions that we must address on a day in and day out basis. And that is why we are here today to hear from you wonderful folks, so that we are better informed and we can go back and tell the Department of Health and Human Services that the taxpayer's dollars are not being properly spent. The cause is good,

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but we want to make sure that the residents of these nursing homes get the best kind of service.

We have a large group, and I would like to find out where you are from. If you are from Manhattan, raise your hand. How about Brooklyn; Staten Island; Queens; and how about the place where I live, Bronx? Bronx has the greater number, but we want to thank you all for coming. It is very important.

I would like to recognize my colleague, Congressman Tom Manton, for whatever words he has to say.

[The prepared statement of Chairman Biaggi follows:]

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PREPARED STATEMENT OF CHAIRMAN MARIO BIAGGI

As Chairman, I am delighted to convene this hearing of the Subcommittee on Human Services. I welcome my colleagues on the Committee, and thank those members who represent Manhattan for joining the Subcommittee today.

Let me begin by welcoming our wonderful audience. We are honored to share this day--Nursing Home Residents Day--with you. We have entitled this hearing, "A Celebration of Nursing Home Residents Day, 1986." Today is a day for the general public to pay tribute to the past, present and future contributions of our nation's one and one half million nursing home residents. It is a day when we recognize that nursing home residents have made significant contributions to the growth, development and progress of this nation. We appreciate the fact that, as elders, nursing home residents offer a wealth of knowledge and experience.

Congress has recognized this day, as both the House and Senate have resolutions in recognition of Nursing Home Residents Day. The Senate version has passed while the House version has a total of 218 co-sponsors, which is the necessary number needed to bring up the resolution on the floor of the House. Even as we speak, the resolution is scheduled for floor action and House passage today. I am proud to be an original co-sponsor of House Joint Resolution 533. I wish to quote one sentence from its text, which captures its major intent:

> "that April 28, 1986 is designated as "National Nursing Home Residents Day," a time of renewed recognition, concern and respect for the nation's nursing home residents."

New York State, which has over 100,000 nursing home residents, also has recognized this day by virtue of a proclamation issued by Governor Mario Cuomo.

This Subcommittee, on behalf of the House Select Committee on Aging, has chosen to celebrate Nursing Home Residents Day by conducting this hearing. I wish to salute the outstanding work of two organizations, one national and one local, but both leaders as advocates for nursing home residents. The first is the National Citizens Coalition for Nursing Home Reform based in Washington,D.C. Their efforts have produced a number of important reforms in place today in nursing homes. Their efforts have also helped to avert attempts to weaken these reforms over the past several years. At the local level, I wish to salute the Coalition for Institutionalized Aged and Disabled, Inc. For the past 13 years, C.I.A.D. has been in the forefront of leadership on behalf of nursing home residents in the New York Metropolitan area. They have provided resident counseling, education and other related services to residents. C.I.A.D. has played an absolutely invaluable role in the development and execution of today's hearing. Their Executive Director, my good friend Vic Rosenthal, has worked day in and day out with the Subcommittee staff to plan all facets of this hearing. We are especially proud that various members of C.I.A.D.,including our first panel of nursing home residents, will testify today.

Nursing Home Residents Day is certainly a time for celebration. Yet, it is also a time for re-examination of how we as a nation are doing with respect to ensuring the highest standard of care for those who live their day to day lives in our nation's 15,000 nursing homes. We acknowledge that we have made great strides in many areas. But we would be less than honest if we failed to realize how many serious shortcomings still exist.

Therefore, a second focus of our hearing today will be on the pressing need to develop and implement new reforms to improve the quality of care in our nursing homes. We will direct our attention to a major new report issued in March, entitled, "Improving the Quality of Care in Nursing Homes." This 300 page, $1.5 million Federal study on nursing homes, was undertaken by the National Academy of Sciences, Institute of Medicine. The specific work for the study was undertaken by a special Institute Committee on Nursing Home Regulation. The Subcommittee is extremely proud to have two distinguished members of this Committee here to present testimony. Drs. Vladek and Gurland will join us later.

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Before discussing elements of the report and some of their recommendations, let me present some relevant background facts as provided by part of the Institute of Medicine Report.

*** In the United States as of 1985, there were a total of 15,000 nursing homes in operation with a total of 1.5 million beds that are certified to receive patients and/or residents under the Medicare and/or Medicaid programs. In New York State, there are a total of 570 certified nursing homes.

*** About 80 percent of nursing home beds in the United States are in for profit facilities. In New York State, the percentage is 51 percent.

*** Occupancy rates in nursing homes nationally is about 90 percent with many having waiting lists.

*** Nursing home care in the United States, according to the study, costs more than $30 billion a year. Two thirds of all nursing home residents receive some assistance from Medicaid.

*** 87 percent of all nursing home residents are over the age of 65. By the year 2000, that percentage is expected to grow to 91 percent. Within the elderly group 70 percent of nursing home residents are over age 75.

The Institute of Medicine which conducted the study was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of medical and other professions for the examination of policy matters pertaining to the health of the public. The specific study was requested by Congress in 1985 following attempts by the Administration to greatly weaken the government's system of protecting residents. The resulting study represents the first ever independent national review of nursing home care and the role of government in assuring quality.

The overriding conclusion of the IOM report confirms concerns which I and other Members of the Select Committee on Aging have had for some time. Let me quote directly from the report: "There is broad consensus that government regulation of nursing homes, as it now functions, is not satisfactory because it allows too many marginal or substandard nursing homes to continue in operation."

Second conclusion: "New stronger regulations focused on patient well-being rather than on facilities and staffing are needed to assure that the 1.5 million residents in our nation's 15,000 nursing homes receive high quality care and experience better quality of life."

The Institute study notes that the nursing home abuses that rocked this state and nation just over 10 years ago "now occur less frequently." However, they stressed, and I fully support the belief, that "profound changes are still needed in regulations in the area of performance standards, inspections and enforcement to ensure continued and expanded improvements."

The simple fact is that this Administration over the past 5 years has weakened the federal commitment to protecting nursing home residents when they should have been strengthening it.

Let me cite two examples:

*** In 1981, federal and state officials were authorized by Congress to ban admissions to nursing homes with serious deficiencies. However, no such bans have ever occurred. Why? Because regulations to implement the new penalty have not yet been issued by the Health Care Financing Administration.

*** Under current Medicaid laws, the federal government now matches every state inspection dollar with 75 cents. The President's FY 1987 budget proposal calls for a reduction of that match to 50 cents.

If this were not enough proof, all one has to do is remember the effort by the Administration in 1982 to reduce the number of nursing home inspections. If one puts this all together, it is a disturbing record indeed.

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Our responsibility as a Subcommittee, full Committee and full Congress is to go forward and adopt the major recommendations from this landmark study. I am proud to say that I have joined as an original co-sponsor of a major new piece of legislation offered by our former Chairman and great friend of all older Americans, Claude Pepper. This legislation, H.R. 4485, is entitled the Nursing Home Residents Bay Protection Act of 1986. It is a comprehensive legislative package to carry forth and expand upon the main recommendations of the Institute's study.

Among the bill's major provisions:

*** It would establish effective and uniform standards of nursing home care. Central among these would be the elimination of the existing two categories of nursing home care, skilled and intermediate care. The one standard would be the skilled.

*** All nursing homes would be required to have a registered nurse on duty at all times.

*** Employees of nursing homes who provide direct care to residents must clear a background check for criminal violations.

*** Both federal and state governments would be able to impose graduated intermediate sanctions for nursing homes found deficient in the provision of care. These sanctions would include civil fines, a ban on new admissions, and placement of facility under temporary receivership.

*** All nursing home inspections would be unannounced and conducted on a random basis at intervals not to exceed one year apart. Inspections are to concentrate on the quality of care of residents.

*** The protection of patient's rights would be a new condition of participation that a nursing home must meet in order to qualify for reimbursement by Medicare or Medicaid.

*** Any nursing home found to have discriminated against the admission of a resident on the basis of payment source, such as Medicaid, would be barred from participating in Medicare or Medicaid.

Another critically important feature of this legislation which I hope to work on separately by virtue of my membership on the House Education and Labor Committee, relates to the Long Term Care Ombudsman Program under the Older Americans Act. Under present law, state agencies on aging are required to use not less than one percent of funds alloted for Title III of the Act, or $20,000, whichever is greater, for the establishment and operation of a long term care ombudsman program. The ombudsman is to investigate and resolve complaints made by or on behalf of residents in long term care facilities, among other responsibilities. H.R. 4485, as well as separate legislation I will introduce shortly, would seek to greatly expand this long term care ombudsman program largely by assuring the ombudsman full access to nursing homes and providing increased resources.

Since the entire Older Americans Act comes for reauthorization in 1987, it is possible that this provision may be one of the first to be acted on by the Congress. I intend to make an improved and expanded ombudsman program one of the major features of the 1987 Older Americans Act amendments.

It is our intent with this hearing today to begin a new process of instituting through appropriate legislation new reforms to improve the quality of life for all nursing home residents. We must recommit ourselves to achieving the dual goals of government regulation of nursing homes. The first is to ensure the safety and high quality of care for residents and the second is to ensure accountability for the large public expenditure involved.

Our purpose today is not to condemn an entire industry. We know of thousands of outstanding nursing homes in our nation staffed by professionals with competence and compassion. Yet, the fact remains this is not a universal condition. Substandard care at even a single nursing home is simply unacceptable, especially when it is in effect being partially or totally subsidized by federal funds.

Nursing Home Residents Day 1986 is the appropriate day to begin our quest for new nursing home reforms. The legislative and regulatory framework governing nursing homes has remained essentially unchanged for the past decade. It is time for the framework to adapt to modern times and respond to modern challenges.

Again, I appreciate all of you who have taken the time to join us today. I now look forward to the testimony of our witnesses.

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STATEMENT OF REPRESENTATIVE THOMAS J. MANTON

Mr. MANTON. At the outset, I would like to thank my colleague, Congressman Biaggi, for inviting me to join him today. I don't have to tell you that Mario Biaggi has been a tireless and effective advocate for senior citizens, and I am pleased to be with him here today at this important hearing on the Subcommittee on Human Resources.

As you know, the House Select Committee on Aging has chosen today's hearing as its way to celebrate Nursing Home Residents Day for 1986. This day was selected by the Congress as a day to recognize the needs, concerns, and experiences of nursing home residents. As an original cosponsor of House Joint Resolution 533, which designates April 28, 1986, as Nursing Home Residents Day, I think today's hearing is the most appropriate way to salute our Nation's 1.5 million nursing home residents.

There are more than 15,000 nursing homes operating in the United States, and two-thirds of those residing in nursing homes receive some assistance from Medicaid. The Federal Government has an important role to play in protecting nursing home residents and insuring that these Federal funds are being appropriately spent.

Today's testimony will provide a timely examination on the progress during the last 10 years in improving nursing home care. Today's hearing will also examine the weaknesses in the Federal regulatory process. We know there are many excellent nursing homes in operation. However, there is still room for improvement.

I am very interested to hear the testimony from the residents, from the people who work in nursing homes, and from the many senior advocates here today. In 1983, the Congress asked the Institute on Medicine to study nursing home care and regulations. I have reviewed their study, and I also look forward to hearing the testimony from the representatives of their committee on nursing home regulation.

The Congress has a keen interest in monitoring nursing home care. The record developed today will aid the Congress in determining how we can improve the quality of care and the quality of life for our Nation's nursing home residents. I look forward to working with Congressman Biaggi, and our good friend and colleague Congressman Claude Pepper in developing legislation which will improve the lives of the nursing home residents of today and tomorrow.

I thank you for attending today's hearing. I thank my fellow residents of Queens for making a good showing. I know you came from a long distance, as well as many others. And I look forward to hearing the testimony.

Thank you, Mr. Chairman.

Mr. BIAGGI. At this time I would like to submit the prepared statement of Congressman Bill Green for the hearing record. Hearing no objections, so ordered.

[The prepared statement of Representative Green follows:]

PREPARED STATEMENT OF REPRESENTATIVE BILL GREEN

Mr. Chairman, I commend your leadership in holding this field hearing today to focus on the problems facing nursing home residents throughout the nation, and

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particularly in New York. Few people are as cognizant of the issues relating to the care of our senior citizens as those of us who represent New York City. The new Institute of Medicine report, "Improving the Quality of Care in Nursing Homes," should provide us with important information for needed policy initiatives.

I was pleased to cosponsor the resolution which designates today as Nursing Home Residents Day and creates a special opportunity for us to explore the concerns of such residents. There are many varied problems which need to be addressed, including the cost of maintaining someone in a nursing home, Medicare and Medicaid coverage—or lack thereof, health care and living conditions, and the very tragic problem of elder abuse.

However, I believe a key element of this entire issue is how we can prevent people from becoming nursing home residents. For those who reside in homes we must do all we can to see that they receive the best care under the most comfortable circumstances possible. But with a significant commitment of resources, we could do our seniors one better: maintain them in their homes and communities, and avoid premature institutionalization.

An integral component, any initiative to reach this goal is improving basic home attendant care, that is, the provision of basic household and personal assistance services. Many of today's elderly could remain at home if they only had some help with basic routine tasks such as bathing, dressing, shopping, cooking and cleaning. Achieving a comprehensive home care system in this country would not only benefit those citizens who could remain in their home and communities, but would most likely ease the demands on nursing homes, so that those who are best served by nursing home care can receive the full breadth of services and quality of care available.

Mr. BIAGGI. Commissioner Janet Sainer.

STATEMENT OF JANET SAINER, COMMISSIONER, NEW YORK CITY DEPARTMENT FOR THE AGING, NEW YORK, NY

Ms. SAINER. It is nice to be here to welcome you.

Congressman Biaggi, Congressman Manton, members of the coalition, and friends and nursing home residents, I am really very pleased to join you today, not only in my own name, but to bring you the warmest wishes from the mayor as you mark Nursing Home Residents Day.

He has asked me to personally convey his deep interest in the issues that you will be examining, and that affect so many elderly New Yorkers and their families. New York City is fortunate to have many fine nursing homes with truly dedicated staff. And I want to salute that dedicated staff.

Moreover, I want to pay special tribute to the Coalition of Institutionalized Aged and Disabled, who have taken such an important leadership and advocacy role in enhancing the quality of life of nursing home residents. I also want to salute the volunteers of the Nursing Home Ombudsman Program, sponsored by my department and the New York State Office for the Aging. All of these are important components in the total picture of nursing home care. And all of your activities become even more important as we look at the dramatic increase in people over 75 and over 85 years of age. Just one small example, even though the New York City population decreased a little between 1970 and 1980, the numbers of those over 85 increased by 37 percent in that decade. And in the last 5 years, it increased by another 30 per cent. And, therefore, we know that these are people—admittedly all of them will not require nursing home care, but there is no doubt that more people than ever will be turning to nursing homes to live out their lives.

The study that some of you will be addressing today entitled, "Improving the Quality Care in Nursing Homes," recently conduct-

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ed by the Institute of Medicine of the National Academy of Science, emphasizes resident's rights. And I think it is a very important emphasis. It puts forth recommendations that challenge us and command the consideration of policy makers, congressional leaders, as well as practitioners and all of you.

Therefore, I am very pleased that the 1986 Nursing Home Residents Day is featuring a very important and appropriate hearing and that Congressman Mario Biaggi and Congressman Tom Manton are here to hear from all of you. I trust that this hearing will take the next step in the process of fashioning a legislative program and implementing measures to ensure quality of care and the best quality of life that is possible for those whose lives depend upon the nursing homes of this City and in this Nation.

And now, I would like to call upon Ruby Seidler, president of the Coalition of Institutionalized Aged and Disabled, to join me right over here, Ruby, while I read the proclamation of the mayor and present it to you in the name of all the residents who are here.

Office of the Mayor, City of New York Proclamation: The City of New York recognizes the contributions nursing home residents have made to the growth and development of our nation, and the wealth of knowledge and experience they bring to an endeavor. Over one million older Americans reside in nursing homes, and one in five older Americans is likely to reside in a nursing home at some time. It is important, therefore, to encourage the continued participation of institutionalized senior citizens in the life of their communities. And to foster reintegration of these citizens into their communities wherever appropriate.

Now, therefore, I, Edward I. Koch, Mayor of the City of New York, do hereby proclaim April 28, 1986 to be Nursing Home Residents Recognition Day in New York City in witness whereof I have hereunto set my hand, and caused the seal of the City of New York to be affixed. Edward I. Koch, Mayor.

It is my pleasure to present this to you.

Ms. SEIDLER. On behalf of the coalition, and all the residents here and the residents throughout the city, I gratefully accept this and hope that we will have many more. I hope that as the years go by there will be more and more people who will be able to participate, and who will live happy and successful lives in their homes.

I thank you.

Mr. BIAGGI. Thank you, Commissioner.

The first witnesses, panel 1, Ruby Seidler, Isabella Geriatric Center, and Teresa Talericio, Beth Abraham Hospital, and Betsy Wycoff, River Manor.

Welcome. We are functioning under a 5-minute rule in order to permit as many people to participate as possible. We know that you have a transportation problem, and that the buses must leave at a certain time. So, please comply with the 5-minute rule, at least for those on the panel. Later on, if we can, whoever would like to make a comment will be allowed 1 minute, no more.

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PANEL ONE: CONSISTING OF RUBY SEIDLER, PRESIDENT, COALITION OF INSTITUTIONALIZED AGED AND DISABLED, INC., AND, RESIDENT, ISABELLA GERIATRIC CENTER: TERESA TALIERICIO, VICE PRESIDENT, COALITION OF INSTITUTIONALIZED AGED AND DISABLED, INC., AND, RESIDENT, BETH ABRAHAM HOSPITAL: AND BETSY WYCKOFF, RESIDENT, RIVER MANOR

STATEMENT OF RUBY SEIDLER

Ms. SEIDLER. Good afternoon, everybody. I am very happy to greet all the residents and friends of residents who have come here to help us celebrate today.

My name is Ruby Seidler, and I am president of the Coalition of Institutionalized Aged and Disabled, which is an organization that is statewide consisting of residents and resident councils of nursing homes and adult homes. We function by trying to do the very best we can in order to make life better for people within the homes.

Of course, it is not a very easy thing. We have met with various organizations over the years, with people from advocacy groups, with the health department, with the health finance department, with surveyors, and with the Academy of Medicine. We have found that they are beginning to listen. There is a glimmer of hope that things will be better for us in the homes.

I also want to thank Mr. Biaggi for convening this hearing of his subcommittee, and we thank him also for his kindness to people who are in nursing homes.

Over the years I have watched and read of Government writing and writing and talking and doing nothing. So, I feel that we are very fortunate that now there is a glimmer of hope that things are going to be done. As I said, I have met with various organizations who work for and with residents and resident councils. We have felt that it is very important that we work with them, and we have found 2 this year, at long last the past 2 years, who have helped us a great deal.

I want to speak primarily of two.

One is the National Citizens Coalition for Nursing Home Reform. In 1984, they sent out questionnaires all through the country and asked that groups of people come together and discuss the questions that they are sending. Our group met 3 different times. Each time we were given questions, and everyone there had an opportunity to answer those questions.

After that, we found out also at a meeting that we had with the Academy of Medicine in Washington for 3 days, they too did the same thing. We met in different groups, we met in workshops, we discussed what was going on, we discussed what could be done and could not be done. And amazingly the two groups came out with practically the same answer. One of the important ones was that residents are more concerned with the quality of life than they actually are with the quality of care. But that, of course, is just a minor thing.

The Academy of Medicine has just published a book, and I was very glad to find in it that some of the things that I discussed in my workshop had been implemented or is trying to be implemented. One of them was private rooms for each person in the home.

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I don't know whether you people could realize, you who are not residents, how disconcerting to live in a room with a stranger. I have visited homes where people stay in the room together with the curtain drawn because they can't stand the sight of one another. I met another woman at a home who calls herself a hobo because she leaves her room early in the morning and spends her entire day walking around sleeping everyplace she can because she cannot stay in the room with her roommate.

Those things are very important, so I do hope that the time will come where everybody will have a room for himself. A doctor that I know who has visited many of the homes in Western Europe say that the people there are utterly appalled at the idea that the great, glorious United States puts two people or more in a room, and expect them to spend the rest of their lives together.

In fact, I was in a home not too long ago where there were six people in the room. And that is very, very difficult. My cry to all the people as we meet at the different places is please treat us as human beings, give us liberty, and give us the quality of life that we can have. And remember, what we want are choices. We want the choices of what we can do and what we cannot do. Choices in the dignity in our lives. We want people working there on the staff who treat us as human beings, who are not rude and crude. People who do not push us around; who do not feel that we just are nothing.

There are many, many homes, and I have spoken to people in many homes throughout the State who have complained about the treatment. They are afraid to record it because of retalliation, either overt or covert. They are a little afraid of saying anything about it.

Mr. BIAGGI. One minute, Ms. Seidler.

Ms. SEIDLER. One minute, my goodness, I didn't even get started.

We suggest that the people be allowed to choose, not only what they can do, but also to work. We find that the administrator of a home is the pinhead of the group. And his attitude, and the way he deals with the people is what is being done by the people under him. He must know that we are human beings and we want things done.

We also feel that by working along with these people, and by talking to the surveyors that here in the future they are going to look at the quality of life as well as the care. Homes who do not qualify, who do not give the people a living that is right and proper, will soon lose their Medicaid.

I have enough here to talk for the past hour, but I have to listen to Mr. Biaggi. So I will end by saying that I hope that as we, the elderly, go through the course of life when we join the parade of people going into a better land, we can go saying people have been kind to us; people have been good to us; we are grateful to them and hope that their lives will be happy for what they have done for us.

Thank you very much.

Mr. BIAGGI. Ruby, your whole statement will be included in the record.

Ms. SEIDLER. I have a lot more than is on that.

Mr. BIAGGI. OK.

[The prepared statement of Ms. Seidler follows:]

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PREPARED STATEMENT OF RUBY SEIDLER, PRESIDENT, COALITION OF INSTITUTIONALIZED AGED AND DISABLED, INC.; AND, RESIDENT, ISABELLA GERIATRIC CENTER

GOOD AFTERNOON, MY NAME IS RUBY SEIDLER. I AM PRESIDENT OF THE COALITION OF INSTITUTIONALIZED AGED AND DISABLED. THIS IS A STATEWIDE ORGANIZATION OF NURSING AND ADULT HOME RESIDENT COUNCILS. I HAVE BEEN A RESIDENT IN TWO DIFFERENT HOMES FOR ALMOST 8 YEARS AND AM PRESENTLY RESIDING AT THE ISABELLA GERIATRIC CENTER. I HAVE VISITED MANY HOMES DURING THESE YEARS.

I WOULD LIKE TO THANK MR. BIAGGI AND THE COMMITTEE FOR CONVENING THIS MEETING AND MR. BIAGGI,PERSONALLY, FOR HIS COMMITMENT TO IMPROVING NURSING HOME CARE. THIS DAY IS AN IMPORTANT DAY FOR ALL NURSING HOME RESIDENTS.

I HAVE SPENT MANY YEARS WATCHING OUR GOVERNMENT IN ACTION - SPENDING MONEY ON STUDIES THAT REMAINED ON PAPER - NO ACTION. I HAVE PARTICIPATED IN NUMEROUS CONFERENCES WITH HHS, HCFA, INSTITUTE OF MEDICINE AND ADVOCACY GROUPS - WITH SURVEYORS AND MEMBERS OF THE STATE LEGISLATURE AND MY CRY HAS ALWAYS BEEN "TREAT US AS MEMBERS OF THE HUMAN RACE - GIVE US THE RIGHT AND FREEDOM TO PARTICPATE IN EVERY FACET OF LIVING - LET US HAVE DIGNITY AND PEACE OF MIND."

MANY OF THE RECOMMENDATIONS PROPOSED IN THE IOM REPORT ARE SIMILAR TO IDEAS OUR COALITION HAS BEEN ESPOUSING FOR MANY YEARS, ESPECIALLY THOSE RELATING TO QUALITY OF LIFE.

THE STUDY BY THE INSTITUTE OF MEDICINE ALSO REACHED CONCLUSIONS SIMILAR TO ANOTHER STUDY CONDUCTED IN 1984 BY THE NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM, IN WHICH I WAS FORTUNATE ENOUGH TO HAVE PARTICIPATED. IT WAS ENTITLED "QUALITY OF CARE: THE RESIDENTS POINT OF VIEW". OVER 400 RESIDENTS THROUGHOUT THE COUNTRY - DURING 3 SESSIONS - WERE ASKED WHAT WERE THE MOST IMPORTANT FACTORS LEADING TO QUALITY OF LIFE AND HOW SURVEYORS CAN DETERMINE WHETHER HOMES ARE REALLY PROVIDING THE BEST CARE. CONCLUSIONS REACHED BY BOTH STUDIES INCLUDE:

> RESIDENTS' RIGHT TO CHOICES IN ALL ASPECTS OF THEIR LIVES; RESPECT FOR INDIVIDUALITY; DIGNITY AND COURTEOUS TREATMENT; IMPROVEMENT IN STAFF ATTITUDES; IMPROVEMENT IN THE RELATIONSHIP BETWEEN STAFF AND RESIDENT - FROM ADMINISTRATOR TO AIDES. IF THE ADMINISTRATOR IS NOT A WARM, CARING PERSON AND DOES NOT GIVE OF HIMSELF TO RESIDENTS - HIS ATTITUDE TRICKLES DOWN THROUGH THE ENTIRE STAFF. ALSO, EVERYONE IN A HOME NEEDS TRAINING.

THE TWO STUDIES SHOW THAT RESIDENTS ARE MORE CONCERNED WITH QUALITY OF LIFE THAN ABOUT PHYSICAL CARE.

IT IS GRATIFYING TO NOTE THAT CONGRESS TODAY RECOMMENDS CHANGES IN FEDERAL REGULATIONS TO REINFORCE WHAT WE, THE RESIDENTS HAVE BEEN FIGHTING FOR. IT HAS EVEN BEEN SUGGESTED THAT RESDIENTS PARTICIPATE IN THE HIRING OF STAFF.

I AM VERY SUPPORTIVE OF THESE IOM RECOMMENDATIONS TO GIVE RESIDENTS A LIVING EN-

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VIRONMENT TO ENHANCE THE QUALITY OF LIFE - A NORMAL LIFE WITH FEW RESTRICTIONS - A HOME THAT IS A DEMOCRATIC HOME, NOT A TOTALITARIAN ENCLAVE WITHIN A DEMOCRATIC COUNTRY. THEY SHOULD BE PART OF DECISION MAKING IN ALL ASPECTS OF THEIR LIVES; PARTICIPATE IN STAFF MEETINGS AND TRAINING ON EVERY LEVEL AND GIVE THE RESIDENTS' POINT OF VIEW ON ISSUES AND DECISION MAKING. THERE ARE RESIDENTS CAPABLE OF DOING SO.

NURSING HOMES MUST BE MORE THAN REPOSITORIES FOR THE ELDERLY - THEIR INDIVIDUAL PHYSICAL, MENTAL, PSYCHO-SOCIAL AND EMOTIONAL NEEDS MUST BE MET. THEY MUST BE HELPED TO BECOME CREATIVELY ACTIVE, NOT ONLY PASSIVELY SO - OTHERWISE THEY DETERIORATE MENTALLY AND PHYSICALLY.

STAFF MUST ENCOURAGE AND HELP THE RESIDENT TO BECOME AS SELF-RELIANT AS HIS PHYSICAL ABILITY ALLOWS. UNFORTUNATELY, IT IS EASIER FOR STAFF AND LESS TIME CONSUMING TO KEEP HIM DEPENDENT. I HAVE HEARD THE COMPLAINT FROM RESIDENTS AND FAMILY AND THEY SPEAK WITH SADNESS AND DESPAIR IN THEIR FACES.

THE ADDITION OF TWO NEW CONDITIONS OF PARTICIPATION AS RECOMMENDED BY IOM, QUALITY OF LIFE AND QUALITY OF CARE, COULD PROVIDE THE NECESSARY INCENTIVE TO IMPROVE THE QUALITY OF LIFE AND CARE IN NURSING HOMES. IF NURSING HOMES KNOW THAT SURVEYORS WILL BE LOOKING FOR WHAT CHOICES RESIDENTS HAVE, HOW STAFF SPEAKS TO RESIDENTS AND WHAT EFFORTS ARE BEING MADE TO MAINTAIN OR IMPROVE RESIDENTS' CONDITIONS, FACILITIES MAY CHANGE THEIR POLICIES. IN THE PAST FACILITIES WERE ONLY FACED WITH SERIOUS DEFICIENCIES WHEN THE NURSING OR MEDICAL CARE WAS SO BAD THAT RESIDENTS' LIVES WERE THREATENED. NATURALLY, SURVEYORS MUST STILL LOOK CLOSELY AT THOSE SERVICES, BUT ENFORCING CONDITIONS ON QUALITY OF LIFE AND CARE MAY RAISE THE LEVEL OF CARE PROVIDED IN FACILITIES BEYOND THE MINIMUM.

THE LINKAGE OF QUALITY OF LIFE TO POTENTIAL ENFORCEMENT ACTION MAY SEND A STRONGER MESSAGE TO NURSING HOMES. IF YOU REPEATEDLY FAIL TO RESPECT RESIDENTS' DIGNITY AND INDIVIDUALITY AND YOU DON'T MAKE EVERY EFFORT TO PROVIDE COMFORT, SUPPORT AND REHABILITATION TO RESIDENTS, YOU MAY LOSE YOUR RIGHT TO RECEIVE MEDICAID FUNDS. THIS LINKAGE MAY HELP TO END THE CURRENT PROBLEM OF FACILITIES WHO HAVE REPEATED VIOLATIONS IN QUALITY OF CARE, BUT NEVER RECEIVE ENFORCEMENT BECAUSE THEY DON'T THREATEN RESIDENTS' LIVES.

I AM ALSO DELIGHTED THE IOM COMMITTEE IS GOING TO STUDY THE BENEFITS OF SINGLE ROOM OCCUPANCY AND HOW THAT SINGLE FACTOR ALONE CAN ENHANCE THE QUALITY OF LIFE. SHARING A ROOM WITH A STRANGER IS A HORRIBLE WAY TO EXIST IN THE FINAL YEARS OF A LIFE - NO PRIVACY - NO MENTAL OR PHYSICAL RAPPORT, DIFFERENT LIFE STYLES, DISTURBING FRUSTRATIONS - A NIGHTMARE. WESTERN EUROPEAN COUNTRIES ARE HORRIFIED TO HEAR THAT THE GREAT U. S. A. ENFORCES SUCH CONDITIONS.

GIVE US A DIGNIFIED OLD AGE - RICH WITH TRANQUILITY. SOME DAY YOU OR YOUR LOVED ONES WILL BECOME ONE OF US.

LET US HOPE THAT WHEN WE MEET NEXT YEAR WE MAY SAY THAT MANY OF THESE RECOMMENDATIONS HAVE REALLY BEEN ACHIEVED.

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STATEMENT OF TERESA TALIERICIO

Ms. TALIERICIO. Hello, everybody, my name is Teresa Talericio. Before starting to say what I have to say, I want to give special thanks to Congressman Biaggi for his support of Nursing Home Residents Day, and to the committee for giving me the chance to testify.

I am a resident of Beth Abraham Hospital, a skilled nursing facility, and vice president of the Coalition of Institutionalized Aged and Disabled. I have lived in Beth Abraham for more than 12 years, and have been very active with the resident council.

Most of the care provided to residents is provided by nurses aides and orderlies. Many of them have received very little formal training, and have virtually no prior experience working with nursing home residents. In New York State, we have been struggling for years to pass a staff training law. Many of the States around the country still have no staff training regulation or law. The IOM Committee has recommended a new standard, which would require that all nurses' aides complete a preservice, state approved training program.

Staff training programs must focus on resident's rights and quality of life issues. It is not enough to know how to bathe a disabled person, or to know how to transfer from her bed to her wheelchair. Staff must know how to listen to the residents, and make sure that care is being provided with as much concern as possible for the resident's comfort. Providing care with compassion, courtesy, and a little warmth, goes a long way toward making each resident feel better about herself or himself. I know that when my care is being provided by an orderly who respects my privacy and dignity, and who will listen when I am complaining about pain, my day will be a whole lot better.

This recommendation, as good as it is, needs to be stronger. Well-trained nurses' aides will not make a big enough difference if they are not supervised by well-trained nurses, and if the home is not managed by a well-trained administrator. From the administrator to the charge nurses, an atmosphere must exist that promotes resident's rights and quality of life. There must be leadership in the home by its managers. The aides must know what is expected of them, and receive the necessary support from their supervisors. If the home is not well managed, aides cannot do their job. You can't give residents the care they need if the home does not have the management to supply or hire staff.

Furthermore, residents should be involved in the training program. For these reasons, the recommendations should be strengthened to make training a condition of participation. And not just for aides, but for doctors, nurses and administrators.

In the same way, training of state surveyors is essential. The Federal Government must take a lead role in these training efforts, and must provide the necessary funds so that every surveyor in the country is well-trained in the PAC's survey method. Surveyors must also be better supervised so they understand how to find and write up deficiencies. Surveyors must be trained so that they can find problems in the home, document them accurately, and help the State build good cases against bad operators.

I want to make one last point about the recommendation on social service. We have spoken about resident rights, quality of life, and moving from medical model to a more complete model with special concern for resident's emotional and social needs. Social workers, if sensitive and well-trained, are the key people to provide support and counseling for residents and in-service training for staff. The recommendation to require one social worker in each facility for 100 or more beds is much too weak. If the IOM Committee and Congress is serious about meeting the total needs of residents and striving for real quality in the lives of nursing home residents, then this recommendation should be strengthened to increase the social service staff in nursing homes, be they large or small.

Thank you very much for listening to me, and for your support of us living in nursing homes. You have made this a very special Nursing Home Residents Day.

Mr. BIAGGI. Thank you very much, Teresa, for a very fine statement.

[The prepared statement of Ms. Talericio follows:]

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PREPARED STATEMENT OF TERESA TALIERICIO, VICE PRESIDENT, COALITION OF INSTITUTIONALIZED AGED AND DISABLED, INC.; AND, RESIDENT, BETH ABRAHAM HOSPITAL

My name is Teresa Talericio. Special thanks to Congressman Biaggi for his support of Nursing Home Residents Day, and to the committee for giving me the opportunity to testify.

I am a resident of Beth Abraham Hospital, a skilled nursing facility, and Vice-President of the Coalition of Institutionalized Aged and Disabled. I have lived in Beth Abraham for more than five years and have been very active with the resident council.

As you can tell, I am in a wheelchair and have been disabled for many years. My disabilities have made me dependent on others to help me dress, bathe and go to the bathroom. Although I have many medical and nursing needs, the attitudes of staff members in caring for me is often more important, as is the availability of stimulating activities and the right to make decisions about the care I receive.

Most of the care provided to residents living in nursing homes is provided by nurses aides and orderlies. As you know many of them have received very little formal training, and have virtually no experience prior to working with nursing home residents. In New York State we have been struggling for many years to pass a nurse aide staff training law. Like New York State, many other states around the country still have no staff training law or regulation. The IOM committee has recommended a new standard which would require that all nurse's aides complete a pre-service, state-approved training program.

Staff training programs must focus on residents rights and quality of life issues. It is not enough to know how to bathe a disabled resident or how to transfer that person from her bed into a wheelchair. Staff must know how to listen to the resident, and make sure the care is being provided with as much concern as possible for the resident's comfort. Providing care with compassion, courtesy and a little warmth goes a long way toward making each resident feel better about her or himself. I know that when my care is being provided by an aide or orderly who respects my privacy and dignity, and who listens to me when I am complaining about being in pain, my day will be a whole lot better.

This recommendation by the committee must be aggressively pursued - we need staff training programs in every state right now. This recommendation would be stronger if it mentioned that the training of staff on residents rights and quality of life should include residents as trainers. In my facility and others across New York State, we have begun to be included in this program. After all, who knows more about residents rights and our most important daily needs than us - the residents.

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This recommendation by the committee, as good as it is, needs to be stronger. Well-trained nurse's aides will not make a big enough difference, if they are not adequately supervised by well-trained nurses, and if the home is not effectively managed by a well-trained administrator. From the administrator to the charge nurses, an atmosphere in the home must exist that reinforces residents rights and quality of life. There must be leadership in in the home by its managers. The aides, who provide most of the care, must know what is expected of them and receive the necessary support from their supervisors.

Many of the problems found in nursing homes are a combination of poorly trained staff and poor supervision. In too many cases I have seen nurses, administrators and doctors set a poor example for the nurses aides. Also, if the home is not well-managed aides cannot do their job. You can't give residents the care they need if the home does not have the management to order supplies or hire enough staff. For these reasons, the recommendation should be strengthened to make training a Condition of Participation, and not just for aides, but also for doctors, nurses and administrators.

Just as the training of facility staff is important, so is the training of State surveyors essential. This is especially important with the new survey program, PACs, which is being implemented. The Federal Government must take a lead role in these training efforts, and must provide the necessary funds so that every surveyor in the country is well-trained in the PACs method. Like with nursing staff, surveyors must be better supervisors, especially so they understand how to find and write up deficiencies. Surveyors must be better trained so that they can find problems in the home, document them accurately and help the State build good cases against bad operators.

Surveyors need much more training in residents rights and interviewing techniques. These are especially important with the New PACs method. In New York State our Coalition has been having on-going meetings with the Health Department to develop good questions for surveyors to ask residents about all aspects of care during the survey process. The Health Department will also include residents in the training program for surveyors, especially on residents rights. We believe that our work with the Health Department is important and should be done in all states to make surveyors much more sensitive to residents.

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One last point I want to make is about the recommendation on social services. So far we have spoken about residents rights, quality of life and changing the emphasis in nursing homes from a medical model to a more complete model with special concern for residents' emotional and social needs. Social workers, if sensitive and well-trained, are the key staff people to provide support and counseling for residents and in-service training for staff. The recommendation of the IOM committee to require one social worker in each facility of 100 or more beds, and exempt smaller or rural facilities of this requirement is much too weak. If the IOM committee and Congress is serious about meeting the total needs of residents and truly striving for real quality in the lives of nursing home residents, then this recommendation should be significantly strengthened to increase the social service staff in nursing homes.

Thank you very much for listening to me, and for your support for those of us living in nursing homes. You have made this a very special Nursing Home Residents Day.

STATEMENT OF BETSY WYCOFF

Ms. WYCOFF. My name is Betsy Wycoff. I have been a resident of River Manor, a health related facility, for less than 2 full years, so I am still in the process of making the necessary adjustments while trying not to become, in the bad sense, "institutionalized."

One of the hardest things to realize is that one still has the rights of a citizen of the United States. The Patient's Bill of Rights is posted, here, there and everywhere; the telephone numbers of the health department and the ombudsman, to whom one may appeal if protests fail, are equally conspicuous. No one uses them, but everyone gripes.

You hear a fellow-patient complaining that he doesn't know what medicine he is taking or why. You know he has a right to be told and that if he makes enough fuss, he will be told. But he probably won't make the fuss and you wonder how much good it would do him to know.

A confused old lady insists on telephoning her son. The staff try to discourage this, but she finally makes the call over a public phone next to the nurse's office. She hangs up in tears. She couldn't say what she wanted to. Whose fault is it, her's for not saying it anyway, or the home's for not giving her some privacy. And so it goes, day by day, in little ways we quit struggling.

Some people do complain to the proper authorities in their home and some bad practices are corrected. It is true that it is largely our own fault that our rights slip away. But most people are unwilling to be troublemakers, and many are afraid that if they are troublemakers, they will in some way get in wrong.

There are remedies. Raising residents rights to a condition of participation should send a strong signal to nursing home staff and surveyors, that our rights to dignity, respect, privacy and participation, are of the utmost importance.

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All nursing homes in this State are required to have resident councils in which problems of general concern may be discussed, and which provide machinery for formal written requests to the administration, which must be answered in writing within 21 days. Any such council is useful as a safety valve for irritation and some are not much more. Others, by hard work, manage to have an influence on how things are done.

The situation would be helped if recommendation 37E in the report was adopted. This calls for each facility to have a, "plan for regular resident participation in the facilities operations and policies and for presentation of resident concerns." This would do something to save us from perpetually being confronted by changes for which we were not prepared, and about which we have not been consulted.

The principal safeguard of patients' rights is the annual inspection by the State authorities. I have lived through one of these, and am now living through another. The halls are made hideous by sudden paint jobs, cleaning of heating systems and the roar of polishing machines. The patients' lives are made hideous by sudden emphasis on "good grooming" and preliminary snap inspections of drawers and closets.

One knows that the inspectors spend time with the nurses going over our charts, and with the heads of various departments, checking their activities. We see the inspectors going in and out. We see them in the dining room checking the food on the plates and consulting with the dietitian. They seldom speak to any of the residents. Last year I did not happen to meet any residents who had exchanged a word with any of them. This year, one of the aides brought an inspector to every room on my floor for a stiff exchange of courtesies. There are reports that this year they may seek out officers of the resident council for real interviews.

In any case, I can think of nothing that would do more to help us, the patients, than what this report describes as a resident-oriented survey. Interviewing residents and relatives, and focusing on residents' rights and quality of life, should give surveyors a much better idea about the quality of care in the home. Meeting with the resident council before the survey and in the exit conference, is the best way to make sure residents really understand the purpose of the survey and are active participants. These are our homes, we should know what is going on and be involved.

Surveys must measure nursing homes as they usually operate, not as slicked up for the occasion. This of course, involves hearty support of the recommendation in the report that the timing of surveys should maximize the element of surprise. This might bring about some nice surprises for the residents and the surveyors. These recommendations give us hope for the future. It is up to Congress and the Federal Government, as the report recommends, to provide sufficient money, more than in recent years, for larger survey teams, stronger ombudsman programs, and better enforcement.

Thank you for this opportunity.

Mr. BIAGGI. Thank you very much, Betsy, and also thank you, Ruby, for your excellent statement and for your leadership in this area. We know you have been involved a long, long time.

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I would like to make some observations, and they have been enunciated by each of the panelists in part. Clearly, there are things we can do. Ruby makes the point, "the residents are more concerned with the quality of life." There is no question that is important. And an atmosphere is developed.

I have visited many nursing homes, and I know when I go in everyone is aflutter, but that is not the normal condition. When I speak to the residents and their families, I am more likely to get the truth. There is an old saying that the fish stinks from the head. Well, if you get an administrator who is not simply a good businessman, it is important that he be a good businessman to operate the nursing home in a good fashion so that it continues to function.

But he needs more than just a business attitude. He needs a human attitude. He must understand the feelings. He must get out and talk to the residents, and have the residents be in a position to talk to him. Very, very important. You know when you walk into a place where there is warmth and there is caring. In many of these places, there aren't these two elements. Many of the nursing homes are simply warehouses for human beings. They are a product. They want those beds filled so that they can make money. As long as the beds are filled and they are making money, that is their principal concern.

Happily, that is not universal. But where it does exist, it must be changed. It must be changed. And what are we asking for, simple things. As you would treat another human being in a decent fashion. As you would treat a loved one. Be courteous, give them dignity, respond to them as best you know how, as best as possible. Because we know sometimes the residents are difficult. But even in their difficulty, please be understanding. Don't be short-tempered, and don't regard them as less a human being because they are moving along in years.

You heard Commissioner Sainer, the people 80 and 85 are living longer. The rate of growth is 30 or 35 percent. That tells all of us, if you are 60, 65, 70, 75, you are not prepared to die. The chances are you will live a long time, and that is the result of a better way of life in this country in the early years. But simply because you are in a nursing home shouldn't subject you to less than human treatment. In many areas it it.

The patients are terrorized, terrorized! They speak furtively when they speak to me. They look about, and you can see their eyes looking about to see who else is around, and they'll talk to you. Well, that should not be. We are talking about individual rights. And it has been said before, and it will be said again, if the administrator cares, he will make sure that his aides care. If the administrator cares, it is in the atmosphere. If the administrator cares, it trickles down.

If the people that he employs do not care, they should be fired—absolutely. I know and I am told that employees are difficult to get. Let me tell you, I rather have an absence of employee, than one that is brutal and cruel and disrespectful. And I don't believe they are difficult to get. I think there are many wonderful people out there who would come in and give care. We have volunteer programs for the children. Grandparents come in. Healthy people give care on a volunteer basis, on a small stipend.

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I mean, just think in terms of human beings. Yes, happily most of them are caring people, but for those who are not, something should be done. As far as the home is concerned, sometimes the administrator and the owner need some special attention. Right now, the nursing homes of America are receiving some $30 billion, $20 billion of which comes from the Federal Government.

Before they can be reimbursed—I offer this as a remedy—before they can be reimbursed, there should be a condition that the residents have their rights regarded. It should not be the announced visits on the part of local, State or Federal inspectors. That is nonsense. I involve myself with Letchworth Village and Willowbrook many years ago. And I didn't announce it. But let me tell you, what I found was a horror. And when I went to Willowbrook, they wouldn't even give me the key until I asserted myself in a very vigorous fashion, and what I beheld was revealed to the world by Giraldo Rivera, if you remember the time. And the conditions started to change because the world saw it. They didn't know it existed, and didn't believe it when they saw it.

The same conditions can happen, and do happen, maybe not as bad, in the nursing homes. But however bad they are, they should not be tolerated. There should not be a cozy relationship between the inspectors and the administrators. Because I am an old cop. I've been a policeman for 23 years, and I know every facet of human frailty. The inspector has great authority. The administrator and the proprietor has a lot at stake. We don't want them being cozy. We don't mind them working together in a cooperative fashion, and that is the spirit of those inspections.

Sometimes the home needs some correction. No malevolence, they just need to be jiggered up a little bit. But clearly, the fundamental element, be decent. Think in terms of the elderly as human beings. Somebody that you would want treated in a nice fashion. If your mother or father was present in that nursing home, you would want them to be treated in the same way. It is as simple as that. That is the inescapable theme.

Mr. Manton.

Mr. MANTON. Mr. Chairman, I think you have expressed much of the sentiment that I feel. I suppose the optimum nursing home would be as if the elderly person were living at home with their children as we had perhaps at an earlier time in this country when we had multiple generations living under one roof. Now, obviously people move away, they get relocated. It is very difficult to do this the way it was done in the past when we were perhaps in a simpler society. But I think the model ought to be that the nursing home be in fact a home with the type of care and tenderness that one would expect to find in ones own home.

Unfortunately, with some of our nursing homes, thank God not all, this is not the case. It has become a big business with 1½ million residents, 15,000 nursing homes, a $30 billion industry. Two-thirds of all of the people in the nursing homes are receiving some kind of Federal assistance. So we have an obligation as members of the U. S Congress to see that these Federal dollars are spent to provide an atmosphere where people have a decent quality of life; where they have choice; where they have privacy; where they are treated humanely by people who really have a feeling for these

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nursing home residents as if they were members of their own family.

This may be a large order, but the fact is that with our growing aging population, our chairman indicated that there are many, many people over the age of 85, and this is the fastest growing segment of our society. We must see to it that these nursing homes are fit, and adequate, and decent places. And I think that is what we will take away from these hearings by hearing from the people that live in the homes, and those who operate them, and people that are involved in the system.

And I think that this a reason to commend our chairman for having this important hearing. Thank you.

Mr. BIAGGI. I would like on this occasion to thank the panels for their contributions.

We don't have questions now, but we will develop some and we will be in touch with you on them. And the reasons we don't impose the questions again is to save time.

Ruby, thank you very much. You are wonderful. Betsy, Teresa, thank you.

Ms. SEIDLER. You spoke more than 5 minutes.

Mr. BIAGGI. We have panel 2, The Institute on Medicine, Committee on Nursing Home Regulation Representatives: Bruce Vladeck, president of the United Hospital Fund of New York City, and Dr. Barry Gurland, director of Columbia University Center for Geriatrics and Gerontology.

Before the panel commences, I want to thank the Coalition of Institutionalized Aged and Disabled, Inc., for the past 13 years CIAD has been in the forefront of the leadership on behalf of nursing home residents in the New York metropolitan area. They have provided resident counseling, education, and other related services to residents. CIAD has been outspoken, consistent, and most important of all for an advocate organization, persistent. They don't just work on Monday. They stay day after day, week after week, month after month, year after year. And that is the only way you can function effectively.

CIAD has played an absolutely invaluable role in the development and execution of today's hearing. Their executive director, and my good friend, Vic Rosenthal, has worked day in and day out with the subcommittee staff to plan all the facets of this hearing.

And we are especially proud that various members of CIAD, including our first panel of nursing home residents, will testify and has testified.

Where is Vic Rosenthal? I think Vic deserves a great hand.

Mr. BIAGGI. We have the two members of the panel right now, who have been responsible for this 300 page book, which spells it out and sets an agenda for all the tomorrows in relation to nursing homes. We are just delighted that they are here, and we congratulate them for this publication, and all of your most meaningful work. Thank you, gentlemen.

Bruce.

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PANEL TWO—INSTITUTE ON MEDICINE, COMMITTEE ON NURSING HOME REGULATIONS REPRESENTATIVES: CONSISTING OF BRUCE C. VLADECK, PRESIDENT, UNITED HOSPITAL FUND OF NEW YORK; AND DR. BARRY GURLAND, DIRECTOR, COLUMBIA UNIVERSITY CENTER FOR GERIATRICS AND GERONTOLOGY

STATEMENT OF BRUCE C. VLADECK

Mr. VLADECK. Thank you, Mr. Chairman, Mr. Manton.

My name is Bruce Vladeck. I am president of the United Hospital Fund of New York, and it was my privilege to serve for about 2½ years on the Committee on Nursing Home Regulation of the Institute of Medicine. The report you just showed, Mr. Congressman, entitled, "Improving the Quality of Care in Nursing Homes," I must confess that my principal response to the completion of the committee's work was in keeping with the old adage that alls well that ends, after 2½ years of hearings and meetings and deliberations and so forth.

There is quite a lot in the report, and rather than attempt any kind of comprehensive summary, given considerations of time, let me just hit on a few points that I think are most important.

First, most importantly, the committee found that despite very significant improvements over the last decade or so in the quality of nursing home care in the United States, there continue to be far too many instances of grossly inadequate care. And perhaps even more importantly, that the average level of care in facilities throughout the United States is not nearly as high as it should be.

Further we found, particularly in terms of the charter of the committee, that given the history of regulations of nursing homes, given the nature of the nursing home market, it is imperative if care is to be improved and the worst abuses eliminated, that the regulations of nursing homes be strengthened and improved. Deregulation may be fine for telephones or transportation, but in not appropriate to protect the lives of nursing home residents and their well-being.

Second, it was clear on the basis of our studies that if we are going to improve the quality of care in nursing homes and quality of nursing home regulation, the Federal role must be significantly strengthened. This is particularly important for those States—of which New York is not one—which currently have the weakest standards or the weakest enforcement activities.

Nonetheless, inadequate Federal standards, inadequate Federal survey procedures, inadequate Federal financial support for State agencies, not only set an unacceptably low floor for nursing home performance nationally, but also constitute a failure on the part of the Federal Government, we believe, to meet its obligations to protect those residents all of whom are citizens and most of whom are direct beneficiaries of Federal Government programs.

I must add in this regard, that the committee in coming to this conclusion, was influenced among other things by a series of court decisions, particularly that in the case now called *Smith* v. *Heckler* that came to much to same conclusion about the continuing obligation of the Federal Government visa vis nursing home quality of care.

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Third, in keeping with what you heard earlier, the committee felt very strongly that since nursing homes are places where people live as well as receive professional services, that regulation must address the quality of life as well as the quality of care. We made a number of specific recommendations about quality of life standards and conditions, and about mechanisms for ensuring through the survey and inspection process that those standards are being met.

At the same time, however, if you recognize that facilities are places where people live, and you care about quality of life, than you have to start with the protection of basic rights of residents, their families, and advocates in the facilities; and with ensuring substantially better mechanisms for the participation of residents and their families and representatives in decisionmaking about aspects of nursing home life. As in other aspects of life in a society like this one, the Government, especially the Federal Government, has a major role to play in ensuring the protection of human rights. And in ensuring that mechanisms exists for people to have adequate control over their own day to day lives.

In the same vein, we felt very strongly that both the standards and the inspection processes should focus much more directly on the residents themselves, rather than on the bricks and mortar or characteristics of the facility, or the contents of its file draws. We recommend that surveyors be required to actually talk to residents, to actually observe the kind of care they receive; and that staffs actually solicit their views, and those of their families and representatives.

Moreover, much of our recommendation revolves around a series of resident centered assessment to be administered at admission and routinely thereafter, to drive much of the rest of the process of standard setting and enforcement. That again reminds everyone in the process that nursing homes exists to take good care of their residents. The resident ought to be the focus of the process, rather than the facility.

If you do that, you can also at the same time eliminate a lot of the most burdensome and least productive aspects of regulations. We are as sensitive to reducing red tape and bureaucracy as anyone else I think. The key again is to focus on actual care given to actual residents, rather than on a series of formalistic, ritualistic, recordkeeping requirements.

Further, it is imperative that we focus our inspectional resources on facilities with the highest risk for bad performance—those with inadequate past performance records, or those with particularly endangered kinds of patients in them, and that we find a way to target a more appropriate share of the enforcement mechanism on the relatively small proportion of facilities with the worst record.

Sixth in my list of priorities, and again there has been reference to it already, if we talk about what actually happens to residents in nursing homes, we are talking about care rendered under the recognition of their concerns responded to largely by aides and orderlies supervised by registered nurses.

It is imperative that we strengthen at the Federal level, mandatory requirements for training, for supervision of aides, and at the same time in order to give that life and meaning, we must strengthen the standards for registered nursing coverage.

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Let me also add that the committee, and especially the subcommittee of which I was a member, spent what seemed like endless months deliberating and studying the relationship between quality of nursing home services, the cost of those services, and reimbursement of nursing homes. And while we were not at all insensitive to the climate of fiscal constraint that governments are caught in, nor were we unaware of the claims the nursing home representatives generally make that in order to improve the quality they need more reimbursement, we were unable to find any systematic demonstration of the fact that higher reimbursement produces higher quality.

In fact, you can go all around the country, and at given level of reimbursement find enormous differences in quality of services, whether the rate is $35 a day, or $45, or as in New York, $100 a day.

Mr. BIAGGI. That prompts a question, and the question is prompted by that additional reimbursement doesn't necessarily improve the quality. If we were to improve the salaries of the personnel, do you think that would improve the quality?

Mr. VLADECK. Only if you use those salary improvements to hire better trained people, or to invest in training only if you provide job ladders and career ladders for them once they are in those jobs. The history in this city, Mr. Congressman, is that reimbursement dollars have been made available to facilities to provide upgrade in compensation for the workers, and the workers have never seen it.

There is currently an experiment in California, where the legislature allocated to the Medicaid Program a lump sum of money on the condition that it all be passed through directly to a wage increase to the workers. Apparently there is some question as to whether or not they have been able to see that 100 percent on the dollar actually gets to the employees.

But if you are only giving the increase without expecting an improvement in performance in terms of qualifications at entry, in terms of training while they are on the job and so forth, I don't think you are going to get it. I don't want to argue against higher wages for people doing tough jobs. But again you have minimum wage workers—thank goodness not in this city, but in many parts of the country, you have aides at minimum wage, or 10 cents an hour or 20 cents an hour over, doing a superb job, and next to them, an aide at the same compensation level doing a crummy job. So, it is important, but it is not the key.

The key is the motivation and skills of the management of the facility—the motivation and skills of the professional staff of the facility. Obviously, there is a point at which if you pay too little, you can't provide decent care for, but that is already covered in the variety of Federal statutes and regulations. The real point is that while the committee felt that we need a lot more research in these areas, and that we should experiment with issues of case mix-based reimbursement, as we are now doing in New York, many of the qualitative changes that we recommend can be implemented very soon without worrying about budget neutrality or cost impact, or any of that kind of thing. Because most of the components of improved quality of care are likely to have no impact whatsoever on

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budgets. And those that do are likely to be rounding or size relative to current expenditure levels.

I say all that really as a way to lead to my concluding remarks, and I appreciate your indulgence on time. As you recall, the Institute of Medicine got into this act because back in 1982 or so, the Health Care Financing Administration proposed a very substantial weakening of the existing Federal regulations. And thanks to the organized advocacy of consumer groups and thanks to the leadership in Congress, like yours, Mr. Chairman, we were able to delay that for a year. And than the Congress the second time around asked the Institute of Medicine to make a study.

But, in fact, the recommendations now formally go back to the same people who originally proposed to weaken the existing regulations. And we have seen no evidence that anyone in the executive branch at the moment has any inclination to do anything very aggressively about the quality of care in nursing homes.

Further, some of the recommendations, such as the merger of skilled and intermediate care of facility standards do require statutory change. Therefore, if we are going to have implementation of the recommendations in this report, we are going to need congressional action. I think H.R. 4485 is a good example of the kind of legislation that will do it, and I haven't been asked to, nor can I really speak to all the details of that, but if we are going to get results out of this report, Mr. Chairman, than we are going to need the Congress to drive that train.

And I want to conclude by saying that I have the greatest confidence and the expectation that you and Mr. Manton and your colleagues will do all that they can. There is a lot of promise in that report, but none of it will be delivered without the Congress taking the next steps.

Thank you very much.

[The prepared statement of Mr. Vladeck follows:]

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PREPARED STATEMENT OF BRUCE C. VLADECK. PRESIDENT, UNITED HOSPITAL FUND OF NEW YORK

Mr. Chairman, my name is Bruce C. Vladeck. I am President of the United Hospital Fund of New York. It is my great privilege and pleasure to appear before you today as part of the observation of Nursing Home Residents Day, in order to give my views on the critically important issue of the current state of nursing homes and their residents.

It was my privilege to serve, from late 1983 through the early part of this year, on the Committee on Nursing Home Regulation of the Institute of Medicine of the National Academy of Sciences which, as you know, has recently issued its report entitled "Improving the Quality of Care in Nursing Homes." My remarks to you today draw primarily on the report of the Committee, along with my own observations and insights derived from the process of the Committee's work.

As you know, the Committee's report exceeds 200 pages, and contains several dozen formal recommendations. It was the result of intensive work on the part of 20 Committee members from a wide variety of backgrounds, who shared little other than considerable expertise about issues of long-term care, and a dedication and commitment to improving the quality of care and quality of life for nursing home residents. Rather than attempting to summarize the sizable results of all that effort, therefore, I would just like to emphasize for you a few points in the report about which the Committee felt strongly, and which I think are particularly germane to current public policy issues.

First, and most centrally, the Committee found that, despite substantial improvements in the quality of care rendered by nursing homes in the United States over the last decade or so, there continue to be far too many instances of grossly inadequate care, and the general level of quality in nursing homes is not as high as it could and should be. Further, it was the clear and explicit conclusion of the Committee that, given the history of the nursing home industry and of the regulation of nursing homes, and especially the characteristics of the nursing home market, it is imperative that regulatory activities, especially at the federal level, be strengthened and improved, rather than vitiated, as had been initially proposed by the Executive Branch. While "deregulation" may be a popular fad in transportation or communications, it is clearly inappropriate for nursing homes, given our past experience, current market characteristics, and the extent of government involvement and obligation in the lives of nursing home residents.

Second, it was clear to the Committee that improvement in nursing home regulation, especially in those states (of which New York, I am proud to say, is certainly not one) with the weakest standards and enforcement systems, depends on a significantly strengthened federal role. Inadequate federal standards and surveillance procedures not only set an unacceptably low floor for the performance of state agencies, but also constitute a failure on the part of the federal government to meet its minimal obligations to beneficiaries of its own benefit programs. I should add, in that regard, that this conclusion was hardly unique to the Committee; indeed, the Committee was extremely aware of, and largely in agreement with, the Tenth Circuit Court decision in Smith v. Heckler in 1984.

Third, the Committee felt strongly that, since nursing homes are places where people live as well as receive professional services, the regulation of nursing homes must address the quality of life in those institutions as well as the quality of care. To this end, we made a number of specific recommendations relative to quality of life standards and conditions which we believe could have an important impact in many facilities throughout the country. At the same time, the Committee gave considerable emphasis to substantial strengthening and protection not only of residents' rights within facilities, but of mechanisms to insure the greatest feasible participation by residents, their families, and their advocates in decisions concerning life in nursing homes. We felt strongly that people should not lose their rights as citizens or as autonomous adult individuals merely by virtue of entry into a health care facility, and that governments have a critical role in assuring protection of those rights.

In a similar vein, we felt that both the standards for nursing home quality and, especially, enforcement procedures should focus much more directly on the residents themselves, rather than on characteristics of the facility. Inspectors and surveyors should be required to actually solicit the views of residents, and to physically observe the sort of care they are receiving, rather than focussing solely on characteristics of the facility itself. Moreover, nursing home care in general should be made much more resident-centered by focussing the provision of care around a careful and regular process of standardized patient assessment and monitoring.

Fifth, the Committee, as sensitive as anyone to minimizing the paper work and other ritualistic requirements so often attendant on any regulatory process, made a number of specific regulations relative to streamlining the process, especially in terms of permitting enforcement agencies to focus on facilities with the worst track records, while minimizing the regulatory

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burden on facilities with relatively good records. Further, we proposed a number of ways in which existing regulations could be condensed or streamlined in order to substantially minimize formalistic but not terribly critical aspects of nursing home performance. In addition, the focus of the Committee's recommendations on patient-centered standards and enforcement should also produce a significantly less bureaucratic process than now prevails.

Sixth, but far from least, the Committee recognized that the actual provision of care in nursing homes relies almost exclusively on nursing aides, supervised by registered nurses. We felt very strongly the necessity for mandatory requirements relative to aide training, for strengthening the minimum standards f r licensed nursing coverage, and for substantially strengthening regulations relative to social services. All the regulatory apparatus in the world will be of only limited value if nursing homes lack adequate staffing from adequately trained and motivated employees with which to actually deliver care.

I should also emphasize that the Committee, and especially a sub-committee of which I was a member, spent what seemed like endless hours considering the issue of the relationship between quality of care, cost of services, and reimbursement systems. We were certainly not insensitive to the cost constraints experienced by all levels of government in the current environment, nor were we unaware of the frequent claims by the nursing home industry that improvements in the quality of care are not possible without substantially increased revenue. We concluded, however, that existing evidence shows no straightforward link whatsoever between level of reimbursement, nursing home costs, and the quality of care; that at any given level of reimbursement, nursing homes provide wildly different quality of services; and that in most instances substantial improvements in the quality of services should be possible without significant additional costs to Medicaid or other payors. I should add, however, that we also concluded that substantially more research was needed on the relationship between nursing home costs, reimbursement, and quality, and that it appeared to the Committee that further development of reimbursement systems sensitive to differences in patient case mix among facilities was probably desirable.

I emphasize the issue of cost and reimbursement at this point because I want to turn now to a set of issues that are really only implicit in the report itself, but which I believe, Mr. Chairman, should be of the greatest importance to this Committee. As you'll recall, the Institute of Medicine was first engaged to look into the issue of nursing home regulation because of proposals from the Health Care Financing Administration to significantly alter

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the current federal regulations relative to nursing homes. That implies two things to me relative to this report. First, implementation of many of the report's recommendations is lodged, in terms of formal governmental structure, with an agency that is on record as having recommended essentially the opposite. Second, if there is to be any success at adoption and implementation of these recommendations, vigorous and continuing Congressional efforts will be necessary.

Mr. Chairman, I am afraid that even those recommendations in this report which could be implemented within the framework of current law will not be, or not be in a sufficiently timely fashion, in the absence of clear Congressional directions to do so. Further, there are of course components of these recommendations, particularly including the merging of standards for skilled and intermediate care facilities, which would require statutory change. Hence, I would strongly urge you to give the most serious consideration to framing the necessary legislation as soon as possible.

If all of the recommendations of the Committee were to be adopted into law, the net budgetary impact would, in terms of the existing federal budget and its deficit, be so small as to be essentially invisible. The quality of life of more than a million American citizens, the majority of whom are direct beneficiaries of government programs, would be significantly improved. I believe the government and citizens of the United States owe those of their fellow citizens who are required by reason of frailty and disability to reside in nursing homes nothing less.

Again, I am very grateful for the opportunity to appear before you today. I would be happy to respond to any questions you might have, or to provide you with any further information you might believe to be helpful.

Thank you very much.

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Mr. BIAGGI. Thank you very much, Mr. Vladeck.

STATEMENT OF DR. BARRY GURLAND

Dr. GURLAND. Mr. Chairman, Mr. Manton, I thank you for the opportunity of appearing today to give testimony.

My name is Barry Gurland. I am director of the Columbia University Center for Geriatrics, and I was asked to reflect a little on what the recommendations of the committee might mean for New York State.

The recommendations of the IOM Committee were intended to introduce a uniformly high standard of care for residents in nursing homes across the entire Nation. It was the conclusion of the committee that there are examples of inadequate and unacceptable care in at least some nursing homes in every State, and New York State being no exception. Thus the implementation of the committee's recommendations will assist New York State as well as other States to improve the quality of care for residents.

New York State, compared with other States, is relatively well placed to welcome, support, and accommodate the changes in regulations specified by the committee. With respect to nursing homes, New York compared with the average for the rest of the country, has a much higher proportion of its facilities operating as skilled nursing facilities, so that bringing intermediate care facilities into line with skilled nursing facilities will not be unduly onerous.

It has more large facilities, thus facilitating the upgrading of staffing patterns and the management procedures that have been recommended by the committee. New York State has more nurses per number of beds, allowing greater attention to be given to the quality of care and quality of life issues that the committee has highlighted. It has a greater proportion of facilities run by not-for-profit organizations, which traditionally have been innovators in models of long-term care.

And it has been relatively active in citing facilities for failing to comply with the conditions and standards of participation, and so should be able to respond well to the suggestions of the committee regarding being active in following up on the detection of failure to comply.

In addition, the New York State Department of Health has developed a reimbursement methodology that matches resident's needs to services and resources, and provides incentives for rehabilitation, discharges, and better outcomes for residents. The committee was very concerned that we should shift attention to achieving the goals of care, rather than being concerned with the mechanics of care. We need to keep our eye on what we want to do in caring for residents.

New York State Department of Health has developed an assessment technique, which by categorizing residents into groups with different clinical and service needs, allows incentives to be applied to achieve outcome goals. It is very similar to the type of assessment which has been recommended by the committee as a basis for monitoring and for providing an information system.

The Department of Health is also tempted to refine the certification process to concentrate scarce regulatory resources on facilities

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which are the most likely to be giving poor care. They use a stringing survey, which is called the Centinal Health Events Survey, in which negative outcome, such as pressure sores or in-dwelling catheters, which often indicate the possibility of mismanaged care and warrant a more intensive investigation, are detected and acted on.

Such approaches have been shown to be at least as successful in detecting serious deficiencies as routinely extensive surveys, and have been recommended by the committee. This is an example in which the committee attempted to not only to lay down clear pathways to achieving goals of good quality care, but also paid attention to the feasibility of it, and sensible economic efficient means of exercising regulatory activity.

Nevertheless, despite these efforts by New York State, which has been somewhat of a leader in some of these avenues, the supply of nursing home beds is relatively tight in New York compared with the rest of the country and reimbursement rates are high, making regulation to protect the consumer even more critical in the State.

Moreover, many of the important reforms recommended by the committee have not yet been introduced in New York State, or not in sufficient degree, and would represent a substantial improvement over the current system. These recommendations have already in part been touched upon by other speakers, and particularly by Mr. Vladeck. I might add that there was a high degree of consensus in the committee as to what needs to be done, and that should add strength to its recommendations. For that reason, there is a lot of redundancy in what I would bring to your attention, and what Mr. Vladeck already has done.

Most particularly, the committee was concerned that the resident should be put on center stage, not only in terms of the goals of how we are trying to shape the long-term care system, but also even in terms of assessing the quality of care and the quality of life in these facilities. We saw the resident as being a strong ally in trying to improve the quality of care at every level. Moreover, we felt that the focus should be more clearly on the care actually given to residents, and on the outcome of care rather than on paper compliance. And we felt that there should be some means not only of giving greater scrutiny to those nursing homes where there might be some problems in care and have suggested some technology for doing that. But we also wanted to reward those nursing homes which appear to have a good level of performance.

We have suggested ways in which that can be done. We felt it most important to strengthen and clarify the role of a consumer advocate and the ombudsman program to increase the power of residents to demand better care. As many have suggested, quality of life is as important if not more important, but let's say as important as quality of care for nursing home residents. The committee was able to take the step to show that quality of life issues can be objectively assessed. They can be brought under scrutiny. These are not matters of mere opinion. They can be looked at with great intensity and objectivity. Thus, there is no reason not to examine quality of life with great detail. We have shown that there are ways to do this.

The requirement for better training for nurse's aides was a matter of consensus in the committee. These are the staff who

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spend so much time with residents, and effect their quality of life. We also felt that there should be greater efforts to protect Medicaid recipients against discrimination in selection of admissions into nursing homes.

To ensure that resident's rights are observed, and that the resident or their representative participates more actively in the decisions that concern them, all decisions, including that relating to their care, and including the evaluation of the care given them in that institution.

We felt that one important force for improving nursing home care is to make what is known in nursing homes more readily available to residents, consumer advocates, and a number of other organizations which can be helpful. We felt, therefore, that it is most important that we have an information system which is carefully collected and amassed and available for analysis and understanding of what is going on in the nursing homes on a periodic and current basis. That is needed nationally, at the State level, and also needed by nursing homes themselves to better manage the care for their residents.

Now, this is a list which scarcely anybody would disagree with. I think it accords with our general value system. It accords with the state of the art. It accords with the advances we have benefited from in knowing how to run better nursing homes over the past 10 years. What I think the committee had done, however, which is much more than merely listing these goals, is that they have provided a level of operational detail. They have implanted these goals in conditions of participation, in the standards of participation, in the survey procedures, in criteria for determining what is noncompliance, and have also linked them into enforcement procedures that have real teeth.

If these recommendations of the committee are carried out, we will achieve the goals that I think we have all espoused.

Thank you very much.

[The prepared statement of Dr. Gurland follows:]

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PREPARED STATEMENT OF DR. BARRY GURLAND, DIRECTOR, COLUMBIA UNIVERSITY CENTER FOR GERIATRICS AND GERONTOLOGY

The recommendations of the committee are intended to introduce a uniformly high standard of care for residents in nursing homes across the nation. It is the impression of the committee that there are examples of inadequate care in at least some nursing homes in every state, New York State being no exception. Thus, the implementation of the committee's recommendations will assist New York State as well as other states to improve the quality of care for residents.

New York State, compared with other states is relatively well placed to welcome, support and accomodate the changes in regulation specified by the committee. With respect to nursing homes, New York, compared with the average for the rest of country.....(Unless otherwise stated data are for 1983 and from the survey of State Health Facility Licensure and Certification Agencies: IOM report.47 out of 51 responded):

.....

Has a much higher proportion of its facilities operating as skilled nursing facilities (so that bringing intermediate care facilities into line with skilled nursing facilities will not be unduely onerous)

*Type:
SNF only: 330/570 (vs 2,504/13,326)
SNF+ICF: 195/570 (vs 5,064/13,326)
ICF only: 45/570 (vs 5,759/13,326)

Has more large facilities (thus facilitating upgrading of staffing patterns and management procedures).

*Size: 121+ beds: 50% (vs only 6 other states have 40% or more of facilities this size)

Has more nurses per number of beds (allowing greater attention to be given to quality of care and quality of life)

*Licensed nurses:SNF/ICF beds per nurse:5.8 (vs only 3 other states with a lower ratio)

Has a greater proportion of facilities run by not-for-profit organisations (which traditionally have been innovators in models of long-term-care)

*Ownership: For profit 51% (vs 70%)
Voluntary 39% (vs 22%)
Public 10% (vs 8%)

Has been relatively active in citing facilities for failing to comply with the conditions and standards of participation.

*A-key deficiencies: Percentage of facilities with one or more: 46% (vs 38 other states with this or fewer deficiencies)

In addition, the New York State Department of Health has developed a reimbursement methodology that matches resident's needs to services and resources and provides incentives for rehabilitation, discharges and better outcomes for residents. The assessment required for this program categorises residents into groups (Resource Utilisation Groups) with different clinical and service needs. It is related in type to the assessments which are recommended by the committee as a basis for a monitoring and information system.

This department has also attempted to refine the certification process to concentrate scarce regulatory resources on facilities which are the most likely to be giving poor care. They use a screening survey to detect Sentinal Health Events which are negative outcomes such as pressure sores or indwelling catheters which often indicate the possibility of mismanaged care and warrant a more intensive investigation. Such approaches have been shown to be at least as successful in detecting serious deficiencies as routinely extensive surveys.

Nevertheless, the supply of nursing home beds is relatively tight in New York...

*Number of beds: 95,727 (vs 1,450,413)
Per 1000 of 65+ group: 43.1 (vs 55.8)

..and reimbursement rates are high...

*Average reimbursement rate: SNF 78.70 (vs 42.88)
ICF 49.40 (vs 35.98)

..making regulation to protect the consumer even more critical.

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Moreover, many of the important reforms recommended by the committee have not been introduced in New York State, or not in sufficient degree,and would represent a substantial improvement over the current system:These recommendations are.....

To focus more clearly on the care actually given to residents and on the outcome of that care, rather than on the capacity for service provision or paper compliance.
To concentrate monitoring activity more specifically on facilities which may be giving inadequate care
To strenghthen and clarify the role of the consumer advocate and the ombudsman program
To give greater emphasis to standardr for quality of life in addition to those for quality of care
To require better training for nurse's aides
To protect medicaid recipients against discrimination in selection of admissions
To ensure that patient's rights are observed and that the resident or their representative participates more actively in decisions that concern them
To make information on the quality of care and life in a facility more readily available to legitimate parties.
To make surveys less predictable and more reliable.
To utilise the enforcement process more vigorously
.....and, most important of all.....
To become part of an information system which will serve both national, state and local needs for monitoring, managing and improving care.

*What kind of information system is needed for regulation and planning?

There should be a standard assessment on each resident.....

Recommendation 3-2: " A new condition of participation on resident assessment should be added. It should require that in every certified facility a registered nurse who has received appropriate training for the purpose shall be responsible for seeing that accurate assessments of each resident are done upon admission, periodically, and whenever there is a change in resident status. The results should be recorded and retained in a standard format in the resident's medical record."

..for management..for regulation..for planning developments in long term care ..it is a large undertaking..designing scope..techniques..instruction manuals..training personnel..... auditing....."With good planning,adequate resources and strong, competent leadership, this set of tasks could be accomplished in 2 or 3 years."

*Priority uses might be
Case-mix controlled outcome standards
Medicaid payment decisions
Resource algorithms
Utilisation review

The national Nursing Home Survey of the NCHS is limited by a small sample size, long intervals (10 years since last), insufficient data on health and function, and absence of longitudinal data.

"The committee was impressed with the paucity of information about nursing homes and their operations..."

Recommendation 7-1: "The Secretary of HHS should order a study to design a system of acquiring and using resident assessment data to meet the legitimate and continuing needs of state and federal government agencies. The Secretary also should order a study to determine the needs for other data about nursing homes that would facilitate regulation and policy development. This study should recommend specific ways to collect analyze, and publish or otherwise make such data publically available."

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In New York State, as well as in the nation, we need to acquire a better understanding of the ways to improve care in nursing homes, over and beyond the implementation of the committee's more immediate recommendations. Important issues requiring further study include:

*What kind of information system is needed for regulation and planning

*How do various methods of Medicaid payment affect the quality of care given to residents

*What effect do controls over the supply of nursing home beds have on the cost, quality and availability of long term care services for those in need

*What training and staffing patterns are needed to provide adequate care to residents of nursing homes

*How should nursing homes be designed to fit the needs of residents

....Without proper support for those research efforts we will be prone to unnecesary error in our efforts to further improve long term care.

Mr. BIAGGI. Thank you very much, Dr. Gurland, and to both of you gentlemen, I want to assure you we have many, many questions for you. But if you would indulge us, we would prefer them to you in writing so that you can respond to us, because we are really constrained on a timewise basis.

But your presence here and your testimony is invaluable. And the work you have done, I am afraid the benefits of it will outlive us all. And it going to be a great authority. We appreciate it.

Thank you very much.

Mr. VLADECK. Thank you.

Dr. GURLAND. Thank you.

Mr. BIAGGI. We have six persons on the next panel. We will take them three at a time. The first is Elma Holder, executive director, National Citizens Coalition for Nursing Home Reform; Joe Michaels, chairperson, New York City Long-Term Care Ombudsman Program; and the third is Cynthia Rudder, director of Nursing Home Community Coalition of New York.

Before they begin, we will have a short recess.

[Whereupon, a short recess was taken.]

Mr. BIAGGI. The hearing is called to order.

Elma Holder.

PANEL THREE: CONSISTING OF ELMA HOLDER, EXECUTIVE DIRECTOR, NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM; JOE MICHAELS, CHAIRPERSON, NEW YORK CITY LONG-TERM CARE OMBUDSMAN PROGRAM; CYNTHIA RUDDER, DIRECTOR, NURSING HOME COMMUNITY COALITION OF NEW YORK; FELIX CASIMIR, VOLUNTEER OMBUDSMAN; LOUIS KRIEGER, LEGISLATIVE DIRECTOR, NEW YORK CHAPTER OF AARP; AND NELLIE PEISSACHOWITZ, BOARD MEMBER, FRIENDS AND RELATIVES OF INSTITUTIONALIZED AGING

STATEMENT OF ELMA HOLDER

Ms. HOLDER. Good afternoon.

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As a representative of the National Citizens Coalition for Nursing Home Reform, I am particularly pleased to present testimony on Nursing Home Residents Day. Congressman, we appreciate your personal attention to quality care in nursing homes on this very special day which offers dignity, celebration, and hope to residents throughout the country.

As a national organization, experienced and committed to nursing home advocacy since 1975, we understand that nursing home reform represents ongoing complex and difficult tasks, therefore, we are grateful to the Committee on Nursing Home Regulation of the Institute of Medicine for its outstanding job of presenting the public with an important tool to use in making needed reforms in the nursing home system.

Many of ideas and recommendations generated by the committee work have been shared by concerned organizations for several years. Still, the study presents some new ways of thinking about some old problems, and some creative ideas for resolving them.

Our experience tell us that this new tool will be only as good as we, the public, decide it will be. Just as the committee members worked diligently to give us this document. We must also now join with others and with each other to begin the long, arduous task of making sure that all the worthy recommendations are implemented. We have already began working with other national organizations, such as the American Association of Retired Persons, and the Association of Health Facility License and Certification Directors, to review, analyze, and move these recommendations forward.

We will furnish our full analysis on the report at a future date to the committee. As requested by this committee, I will focus my attention today primarily recommendations that require Federal action. We strongly support action to elevate resident's rights regulations, to a full condition of participation, to be on the same par with others such as nursing and dietary services. Although legislation should not be absolutely necessary to require this, proposals for legislation to implement a full bill of rights in the Social Security Act, would no doubt provide strong backing for this critical component of regulations.

A federally sanctioned bill of rights could help assure that residents can take part in decisionmaking regarding day to day facility operations. Another important recommendation of the IOM Committee. Many of the recommendations and needed reforms regarding quality of life factors in nursing homes are woven into the rubric of resident's rights.

The IOM Committee has given well-deserved recognition to the National Long Term Care Ombudsman Program, and has made several constructive recommendations to strengthen it. With the right support and strength, the Ombudsman Program can provide valuable services to residents in nursing homes and board and care facilities. At the present time, nationally we spend less than $1 per resident, per year, for this critical program designed to protect residents. To increase this amount to at least $5 per resident per year, could mean substantial improvement in the protection that residents now receive. We urge your committee to continue to strengthen its legislative proposal supporting the Ombudsman Program, incorporating the recommendations of the IOM Committee.

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It is also critical that the Administration on Aging be urged by congressional leaders to upgrade their services in support of this important program.

The IOM Committee recommends that through Federal legislation, we dispense with the distinctions between levels of care, intermediate care and skilled nursing care. This needs to be accomplished because it presents barriers to good care for far too many residents. Hundreds of nursing home residents have suffered needlessly because of moves or transfers made as a result of this artificial requirement, which no one supports or understands.

Through past hearings and activities, the Select Committee on Aging has recognized the importance of ending discriminatory practices against potential recipients of Medicaid services, or Medicaid beneficiaries in nursing homes. We hope you will act on the IOM recommendation, which would prohibit facilities from imposing different standards of admission, transfer, discharge, and service for older persons based on source of payment.

It is also important to adopt legislative changes to require nursing homes that do not fulfill their contractual obligation with the Government to provide quality services for each of their residents, as they are supposed to do. Nursing home residents should not be the ones to suffer because of the failure of the system to adequately maintain standards. We should not have to move nursing home residents, or close down facilities, in order to rid ourselves of poor providers of care. In this regard, we hope congressional leaders will see the wisdom of ensuring that State survey and regulatory programs have all the resources that they need in order to fulfill their role as protectors of residents. As stated before today, State regulatory agencies must have enough well-trained surveyors and back up support to enforce regulations.

Our agency believes in the strong leadership and oversight rule of the Federal Government so strongly stated in this Institute of Medicine report. The public wants and expects strong protections for its fellow citizens who choose or must live in nursing homes. At the same time, we know that many states, such as New York, have implemented new protective programs which should be supported through Federal flexibility for state innovations as long as consumers endorse such programs.

As experienced consumers, we know that regulation and legislation are not the only answers to nursing home reform. We appreciate the recognition of the IOM Committee, that it has given to the role of consumer groups. We expect to continue our part to help organize and support organizations, consumer groups, and Ombudsman programs, which can visit nursing homes on a weekly or even a daily basis. These local and State groups are important. They help monitor care, advocate individually for the rights of residents, and help nursing home providers generate new services to make high quality care possible. The New York groups participating in this hearing, provide outstanding models in innovation and motivation for groups in other States.

In closing, it is also important to note our strong endorsement of the comments and recommendations of the Coalition For the Institutionalized, Aged and Disabled here in New York. Especially its recognition of the need for improvement of conditions for nursing

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home workers. The voices of residents throughout the country advocate regularly on behalf of nursing home staff, who are so critical to quality of care.

Finally, let us continue to listen to and most importantly to work with nursing home residents for their own self-advocacy and empowerment, a symbol of this very special Nursing Home Residents Day.

Thank you.

Mr. BIAGGI. Thank you very much, Ms. Holder.

Mr. Michaels.

STATEMENT OF JOE MICHAELS

Mr. MICHAELS. My name is Joe Michaels, and I thank you for inviting me, Chairman Biaggi, Mr. Manton. It is nice to see you looking as though the years do not touch you after all of these years, Mr. Chairman.

I am here as a board member of the Community Council of Greater New York, and as the chairman of the Advisory Committee to the Council sponsored by the New York City Long-Term Care Ombudsman Program. I am going to extrapolate mostly and read just a little bit of this because I would rather talk about things that I have seen and know something about.

One of the things that I think is most important about this entire IOM proposal is the question of regulation. There seems to be a kind of a feeling among people in some areas that regulation is not required, which is to my mind a horror. We have, particularly when you are involved in ombudsman programs, case after case where even in New York where the regulation is better than in most States, it is not what it could be.

I offer you just one example, and remember we are talking about helpless people who can do nothing about the conditions in which they live and who regulates those conditions. Back in 1984, the Sheepshead Nursing Home, a place where we do not have an ombudsman, unfortunately because of finance and other factors, which I will get to later. We can only have ombudsman for about 10,000 of New York's 40,000 beds.

But our staff got a telephone call from the patients because conditions, as we saw when our people went there, were to say the least, terrible. Nevertheless, these people wanted to stay. We have a habit, from fear perhaps about what we see for ourselves, or what we do not want to associate with, we have a habit of depersonalizing people who live in nursing homes. But they are individuals, and they wanted to stay where they were because it was a community and they knew each other. Not much of a community, but a community.

Well, when the State went and took a look, they agreed that things were really not what they should be. I can tell you that the food was atrocious. Our staff couldn't identify what it was by looking at it, except it seemed to be orange. Almost everything seemed to be orange. Everyone agreed the situation was intolerable. The State wanted to close it down. We have run into that before at Beth Rifkin in Staten Island, to be specific, as though there were nursing homes in quantity and we could afford to close them down.

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Actually, there are receivers out there, which doesn't seem to be generally known as much as it could be, who can and will take over nursing homes. Anyway, in this particular case, nothing very good happened immediately because the judge, when they decided it would stay open, appointed a receiver and said receiver was the administrator's brother-in-law.

For a very short time, conditions did improve and then they deteriorated to a totally unsatisfactory situation. Imagine, if you can, and I know you can because you have run into these things before, but we had people being brought to the dining room 4 hours in advance of eating in the morning and strapped into their chairs, just sitting there. Because that was the way they ran this place.

Now, I am happy to say that this is finally resolved, and that there is a good administrator today. But we are talking about a year and a half in the lives of people who are 86 or 87 years of age. With proper regulation, it wouldn't have happened. And it happens in far too many places. The Sheepshead Nursing Home is just one example.

I must say that when we talk about nursing homes, you can never be talking about a desirable place. There are, I know, some people who have a contented life because they have friends and they can live in part of the community. But for the most part, nursing homes are not nice places. They are dreadful places.

In another incarnation, I am also a board member of PRIDE, which comes out of St. Vincent's Hospital in New York, whose purpose is keeping people when they can possibly be kept out, frail elderly people out of nursing homes. I say this because this is a dehumanizing situation. It is a terrible situation. The people find themselves there where they find themselves helpless and out of control of their own lives. If they can possibly be kept at home, much more attention should be given to that than has been.

One of the things that shocks me is that we don't even have the statistics. They keep on telling us, one experiment after another tells us that it is cheaper to keep people at home. It may be true in some instances, but we have not even come up with the statistics to know one way or another if this is so. I hope your committee will give some attention to that. I think it is an extremely important subject.

Now, you may know that New York State has begun a new system by which it reimburses nursing homes. We told the State that we feared an unintended consequence would be the involuntarily grouping of patients within a facility according to the nursing or rehabilitative care required, thus forcing patients to leave rooms and floors they have sometimes shared for many years. We are talking about a depersonalizing experience again. Why? In the name of efficiency.

State officials agreed this possibility existed, and disagreed that it was necessarily bad. Because people might, grouped appropriately, get better and have more efficient care. No, it was just as though these were people who were to be stuffed into various slots. Bundles of resource needs to be distributed most efficiently, not human beings.

I suspect that it is a mistake that there are States in which there are no volunteer ombudsman. I think that the volunteer ombuds-

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man, not the paid ombudsman, is a necessary component of any system that is going to work. Because think of yourself, you have been to nursing homes, gentlemen, and you know what they are like. Think of yourself as a professional who has to do this, even if your a conscientious, every day of your life, 5 days a week, spending your time looking at people who are very ill, and worrying about your own loved ones and possibly thinking of yourself in that situation. It becomes a case of wanting to be personalized.

We feel that it is absolutely necessary for people to speak head to head with the patients. It is the only way to really know what is happening, but if you are a professional and you have to do this day, after day, after day, after day, it is fairly logical that you should start talking to the administrators; start talking to the people who look and sound like you who don't have serious problems that you are getting very, very sick and tired of hearing about.

But the volunteers, and you are going to be hearing from Mr. Felix Casimir, one of ours. An extraordinary man who gives of both his own time and his own resources to do this. But these are people who do wonderful, wonderful things.

This depersonalizing thing, I happen to have an elderly cousin who for years prided herself on her independence. She was a nurse. She was a lieutenant in World War I in the nursing corps. She took care of herself all of her life. Last fall, at age 90, she finally was falling apart. And I told her, "Ann, I think you should go to a nursing home." She was horrified at the mere thought of losing her independence because she used to go to the senior center. She painted, she did things, she prided herself on getting around by herself, and living by herself, and being an independent person. But she couldn't do it anymore.

We don't think of these things; all I could think of was, "Ann, you should be in a nursing home." And I got her into one of the best in New York, run by very nice people. You can't ask for more as long as we are speaking of a nursing home. But at that point, gentlemen, although she is still alive, she doesn't want to be. Her life is gone. She tells me that she just hopes and prays that one morning she will not wake up.

She said to me once, "You don't understand what my independence meant to me. That was everything in my life, and now it is gone and I have no reason to be alive."

The portion about money. Difficult to speak of at this time in our history. I don't know why, the country we are told gets more and more prosperous, but we are told by the administration that we have to have less and less. Well, we have the sum to take care of 10,000 people out of the 40,000 beds in New York. It is nowheres near enough. The money should be there.

All I can say in conclusion, gentlemen, is that it has been said that a nation can be judged by the way it treats its most helpless citizens, who are, of course, the old and the very young. And on both counts so far as our country is concerned today, I feel that, the most kindly way I can put it is that the jury is still out.

Thank you.

Mr. BIAGGI. Thank you, Mr. Michaels.

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STATEMENT OF CYNTHIA RUDDER

Ms. RUDDER. The Nursing Home Community Coalition of New York, a coalition of over 30 statewide consumer organizations, applauds the final report issued by the Institute of Medicine Committee on Nursing Home Regulation.

We were very active in 1982 in helping to convince the Health Care Financing Administration not to implement its proposed changes in the nursing home certification procedures. As you know, of course, after much public and legislative concern, all proposed changes were dropped and a study of the Nation's nursing home regulations was undertaken by the committee.

As expected, the final report of this committee raises serious concerns and makes excellent recommendations for change. I am not going to be able to read this whole thing, but I will jump around. I have submitted copies.

Mr. BIAGGI. Your statement will be included in the record.

Ms. RUDDER. We agree with most of the recommendations in the report. I would like to focus our testimony on the recommendations made in the areas of surveillance and enforcement, and to talk specifically to New York State regulatory systems, and how that might relate.

Once again, New York State seems to be in the forefront of health care change. New York State has already, or is in the process of instituting many of the suggestions discussed in the areas of surveillance and enforcement. Still, consumers and advocates of nursing home care in New York State see many serious instances of inadequate, at times dreadful care, and poor quality of life in the State's nursing homes.

When the report discusses, "in and out facilities that are chronically out of compliance when surveyed, that temporarily correct their deficiencies, and then quickly lapse into noncompliance until the next survey", it is placing its finger on one of New York State's major problems. Recurring problems in New York State of a number of these repeat violators; nursing homes that have deficiencies in the same areas year after year, and the length of time it takes from the moment the deficiency is cited to when corrective enforcement action is taken, it has not been unusual in the past for 1 to 2 years to pass before a case is settled.

While aware that some of the State programs that have been recently implemented will need time for review, I still think that a number of the major recommendations in the area of surveillance and enforcement made by the committee would help in New York State.

I will skip around to some of our recommendations. Under surveillance, Federal support is definitely needed. Although HCFA funded a New York State 3-year demonstration project in 1983 to develop a patient outcome oriented survey, it has not yet agreed to allow New York State to integrate this new system with the new federally mandated surveillance system, which NHCC, and other consumers across the country, believe is not ready to be implemented in its present form. I am speaking, of course, of PAC's.

The State has studied, evaluated, and modified its system over the last 3 years. We believe there are many strengths in the State's

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present system, which will in many ways bolster the new Federal process. New York is ahead of the game, let it use its experience. In concurrence with Elma, we feel that HCFA must recommend and urge innovation among all the States, and then try and get them to try some of these things out.

Federal support of surveyor training is needed. HCFA needs to increase its training efforts, and to support surveyor training in New York State. HCFA has devoted too little time and money for the crucial training needed to help make its new survey program a success.

Even in New York State, which has devoted much time to surveyor training for its demonstration project, time and money will be needed to train surveyors for the new system. More monitoring of surveyor performance is needed. The question of surveyor objectivity and reliability is of paramount importance in the evaluation of nursing home care. Even though New York State's new surveillance program tried to eliminate much of the surveyors objectivity, surveyor judgments are still frequently inconsistent.

We believe that more monitoring of surveyor performance by both the State and HCFA must be done, and results must be included in on-going surveyor training all across the country.

More Federal oversight is needed. HCFA must monitor the state regulatory performance more actively. There must be enough Federal surveyors within each State, so that a large random sample of nursing home surveillance activities can be examined. HCFA staff should be available for consultation if needed. A joint effort must be carried out to examine what can be done to trigger surprise visits. HCFA should work with states to improve the whole area of surveillance.

Under the area of enforcement, we believe that HCFA should work with the States to diminish the amount of time it takes to bring effective enforcement action against a facility. HCFA should examine State enforcement procedures to find out why in one instance a problem can be resolved in a few months, and then in another, years can go by while the facility's residents remain in serious trouble.

Mr. Michaels, you mentioned a facility, Beth Rifkin, which was closed in almost a blink of an eye. Then you had a Sheepshead, which has gone on for 1½ years. In New York State, although they have written detailed enforcement procedures, there are many instances where facilities have been in and out of compliance for a long time. Or more often, in and out of compliance year after year. It is important to find out why.

I think when the report talks about need for specific guidelines for survey followup procedures, I think this will have great effect in New York. There must be specific criteria for evaluating a plan of correction that the facility submits when they have care problems. If you look at any State health department file, you will see many, many different ways that plans of corrections have been filled out, and many different decisions made by different surveyors as to whether they would accept it or not.

There must be a limit on the number of plan of corrections that a facility can submit. What happens very often is that a facility is given a list of deficiencies, submits a plan of correction, it is found

out not to be good enough, it goes back to the facility, they submit a new one, and sometimes it goes back. This is a time process while the residents and the problem stays in the facility. There has to be more than one followup visit to a facility found out of compliance with care, even if the first followup demonstrates full compliance.

We have seen this in New York State, a facility will be out of compliance; a followup is done, and the facility is in compliance. There is not another followup, and then the facility remains out of compliance until the next annual visit. There has to be ways in which not only are there surprise visits, but there are more than one followup care.

In addition to these recommendations, and I will hand you a few more details, I would just like to generally mention a couple of issues that the report mentioned that we are in very strong agreement with: nurse aide training, disallowance of Medicaid discrimination, and access to nursing homes for consumers and their advocates, and consumer access to facility costs reports, and access to one's own medical records.

We urge you to take steps to encourage HCFA to delay its implementation of its mandated surveillance process until that process has been made more effective. And we urge you to urge HCFA to implement the recommendations of the report, as well as to make sure that HCFA has the funds it needs to care for our Nation's frail elderly.

Thank you.

[The prepared statement of Ms. Rudder follows:]

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PREPARED STATEMENT OF CYNTHIA RUDDER, DIRECTOR, NURSING HOME COMMUNITY COALITION OF NEW YORK STATE

THE NURSING HOME COMMUNITY COALITION OF NEW YORK STATE (NHCC), A COALITION OF OVER 30 STATEWIDE CONSUMER ORGANIZATIONS, APPLAUDS THE FINAL REPORT ISSUED BY THE INSTITUTE OF MEDICINE COMMITTEE ON NURSING HOME REGULATION. NHCC WAS VERY ACTIVE IN 1982 IN HELPING TO CONVINCE THE HEALTH CARE FINANCING ADMINISTRATION (HCFA) NOT TO IMPLEMENT ITS PROPOSED CHANGES IN THE NURSING HOME CERTIFICATION PROCEDURES. AS YOU KNOW, AFTER MUCH PUBLIC AND LEGISLATIVE CONCERN, ALL PROPOSED CHANGES WERE DROPPED AND A STUDY OF THE NATION'S NURSING HOME REGULATIONS WAS UNDERTAKEN BY THE COMMITTEE.

AS EXPECTED, THE FINAL REPORT OF THIS COMMITTEE RAISES SERIOUS CONCERNS AND MAKES EXCELLENT RECOMMENDATIONS FOR CHANGE.

NHCC IS IN COMPLETE SUPPORT OF THE SUGGESTIONS RELATED TO THE NEED FOR CONSUMER INVOLVEMENT, THE NEED FOR SPECIFICITY OF STANDARDS OF CARE AND THE IMPORTANCE OF THE QUALITY OF LIFE IN NURSING HOMES. SINCE WE ONLY HAVE FIVE MINUTES TO GIVE OUR TESTIMONY, WE WOULD LIKE TO FOCUS ON THE RECOMMENDATIONS MADE IN THE AREAS OF SURVEILLANCE AND ENFORCEMENT PROCEDURES AND THEIR RELATION TO THE NEW YORK STATE REGULATORY SYSTEMS.

ONCE AGAIN, NEW YORK STATE SEEMS TO BE IN THE FOREFRONT OF HEALTH CARE CHANGE. NEW YORK STATE HAS ALREADY, OR IS IN THE PROCESS OF, INSTITUTING MANY OF THE SUGGESTIONS DISCUSSED IN THE AREAS OF SURVEILLANCE AND ENFORCEMENT. IT HAS CREATED TOOLS FOR PERIODICALLY MEASURING PATIENT AND RESIDENT MEDICAL AND STAFF NEEDS. IT HAS USED OUTCOME ORIENTED TWO-STAGE SURVEYS FOR THE LAST THREE YEARS. IT HAS RECENTLY INSTITUTED A CASE-MIX STRATIFICATION SYSTEM FOR MEDICAID REIMBURSEMENT WHICH WILL BE USED BY STATE SURVEYORS TO TRIGGER OFF-CYCLE, OR SURPRISE, VISITS TO FACILITIES WHOSE CASE-MIX CHANGES SIGNIFICANTLY. AND, IT HAS ALL OF THE ENFORCEMENT ACTIONS MENTIONED IN THE REPORT AT ITS DISPOSAL, INCLUDING THE BAN ON NEW MEDICAID ADMISSIONS.

STILL, CONSUMERS AND ADVOCATES OF NURSING HOME CARE IN NEW YORK STATE SEE MANY SERIOUS INSTANCES OF INADEQUATE, AT TIMES DREADFUL, CARE AND POOR QUALITY OF LIFE IN THE STATE'S NURSING HOMES. WHEN THE REPORT DISCUSSES "IN-AND-OUT" FACILITIES "THAT ARE CHRONICALLY

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OUT OF COMPLIANCE WHEN SURVEYED...(THAT) TEMPORARILY CORRECT THEIR DEFICIENCIES...AND THEN QUICKLY LAPSE INTO NON-COMPLIANCE UNTIL THE NEXT SURVEY", IT IS PLACING ITS FINGER ON ONE OF NEW YORK STATE'S MAJOR PROBLEMS. RECURRING PROBLEMS IN NEW YORK STATE ARE THE NUMBER OF THESE REPEAT VIOLATORS - NURSING HOMES THAT HAVE DEFICIENCIES IN THE SAME AREAS YEAR AFTER YEAR - AND THE LENGTH OF TIME IT TAKES FROM THE MOMENT A DEFICIENCY IS CITED TO WHEN EFFECTIVE ENFORCEMENT ACTION IS TAKEN. IT HAS NOT BEEN UNUSUAL IN THE PAST FOR ONE TO TWO YEARS TO PASS BEFORE A CASE IS SETTLED. WHILE AWARE THAT SOME OF THE STATE PROGRAMS DISCUSSED EARLIER HAVE RECENTLY BEEN IMPLEMENTED, AND NEED TO BE EVALUATED OVER TIME, NHCC BELIEVES THAT MANY OF THE OTHER RECOMMENDATIONS MADE BY THE COMMITTEE WOULD HELP TO MAKE NEW YORK STATE'S SURVEILLANCE AND ENFORCEMENT SYSTEMS MORE EFFECTIVE. NHCC URGES THE LEGISLATURE TO ENCOURAGE HCFA TO REQUIRE ALL THE RECOMMENDATIONS IN ALL THE STATES.

SURVEILLANCE

1. FEDERAL SUPPORT IS NEEDED. ALTHOUGH HCFA FUNDED A NEW YORK STATE THREE YEAR DEMONSTRATION PROJECT IN 1983 TO DEVELOP A PATIENT OUTCOME ORIENTED SURVEY, IT HAS NOT YET AGREED TO ALLOW NEW YORK STATE TO INTEGRATE THIS NEW SYSTEM WITH THE NEW FEDERALLY MANDATED SURVEILLANCE PROGRAM (WHICH NHCC AND OTHER CONSUMERS ACROSS THE COUNTRY, BELIEVE IS NOT READY TO BE IMPLEMENTED IN ITS PRESENT FORM). THE STATE HAS STUDIED, EVALUATED AND MODIFIED ITS SYSTEM OVER THE LAST THREE YEARS. NHCC BELIEVES THAT THERE ARE MANY STRENGTHS IN THE STATE'S PRESENT SYSTEM THAT WILL, IN MANY WAYS, BOLSTER THE NEW FEDERAL PROCESS. NEW YORK IS AHEAD OF THE GAME: LET IT USE ITS EXPERIENCE. IN ADDITION, NHCC URGES HCFA TO STAND BEHIND THE SUCCESSFUL DEMONSTRATION PROGRAMS CARRIED OUT IN THE DIFFERENT STATES. HCFA SHOULD ENCOURAGE OTHER STATES TO TRY SOME OF THESE INNOVATIVE APPROACHES.

2. ADDITIONAL FEDERAL FUNDING IS NEEDED. NHCC AGREES WITH THE COMMITTEE'S RECOMMENDATION THAT THERE SHOULD BE FULL FEDERAL FUNDING FOR ALL SURVEY AND CERTIFICATION ACTIVITIES. STATES CANNOT DO ALL THAT IS NECESSARY WITHOUT THE NECESSARY FUNDS.

3. FEDERAL SUPPORT OF SURVEYOR TRAINING IS NEEDED. HCFA NEEDS TO INCREASE ITS TRAINING EFFORTS AND SUPPORT SURVEYOR TRAINING IN NEW YORK STATE. HCFA HAS DEVOTED TOO LITTLE TIME AND

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MONEY FOR THE CRUCIAL TRAINING NEEDED TO HELP MAKE ITS NEW SURVEY PROGRAM A SUCCESS. EVEN IN NEW YORK STATE WHICH HAS DEVOTED MUCH TIME TO SURVEYOR TRAINING FOR ITS DEMONSTRATION PROJECT, TIME AND MONEY WILL BE NEEDED TO TRAIN SURVEYORS FOR THE NEW SYSTEM.

4. MORE MONITORING OF SURVEYOR PERFORMANCE IS NEEDED. THE QUESTION OF SURVEYOR OBJECTIVITY AND RELIABILITY IS OF PARAMOUNT IMPORTANCE IN THE EVALUATION OF NURSING HOME CARE. EVEN THOUGH NEW YORK STATE"S SURVEILLANCE PROGRAM TRIED TO ELIMINATE MUCH OF THE SURVEYOR SUBJECTIVITY, SURVEYOR JUDGEMENTS ARE STILL FREQUENTLY INCONSISTENT. NHCC BELIEVES THAT MORE MONITORING OF SURVEYOR PERFORMANCE BY BOTH THE STATE AND HCFA MUST BE DONE AND RESULTS MUST BE INCLUDED IN ON-GOING SURVEYOR TRAINING ALL ACROSS THE COUNTRY.

5. MORE FEDERAL OVERSIGHT IS NEEDED. HCFA MUST MONITOR STATE REGULATORY PERFORMANCE MORE ACTIVELY. THERE MUST BE ENOUGH FEDERAL SURVEYORS WITHIN EACH STATE SO THAT A LARGE RANDOM SAMPLE OF NURSING HOME SURVEILLANCE ACTIVITIES CAN BE EXAMINED. HCFA STAFF SHOULD BE AVAILABLE FOR CONSULTATION, IF NEEDED. A JOINT EFFORT MUST BE CARRIED OUT TO EXAMINE WHAT COULD BE DONE TO TRIGGER SURPRISE VISITS. HCFA SHOULD WORK WITH THE STATES TO IMPROVE SURVEILLANCE.

ENFORCEMENT

1. MORE FUNDS MUST BE GIVEN FOR FEDERAL AND STATE ENFORCEMENT.

2. HCFA SHOULD WORK WITH THE STATES TO DIMINISH THE AMOUNT OF TIME IT TAKES TO BRING EFFECTIVE ENFORCEMENT ACTION AGAINST A FACILITY. HCFA SHOULD EXAMINE STATE ENFORCEMENT PROCEDURES TO FIND OUT WHY IN ONE INSTANCE A PROBLEM CAN BE RESOLVED IN A FEW MONTHS AND IN ANOTHER YEARS CAN GO BY WHILE THE FACILITY'S RESIDENTS REMAIN IN SERIOUS TROUBLE. IN NEW YORK STATE, ALTHOUGH THEY HAVE WRITTEN DETAILED ENFORCEMENT PROCEDURES, THERE HAVE BEEN MANY INSTANCES WHERE FACILITIES HAVE BEEN OUT OF COMPLIANCE FOR A LONG TIME, OR MORE OFTEN, IN AND OUT OF COMPLIANCE YEAR AFTER YEAR. IT IS IMPORTANT TO FIND OUT WHY.

3. MORE SPECIFIC GUIDELINES ARE NEEDED FOR SURVEY FOLLOW-UP PROCEDURES.

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A. THERE MUST BE SPECIFIC CRITERIA FOR EVALUATING A PLAN OF CORRECTION (POC) SUBMITTED BY A FACILITY FOUND TO HAVE CARE PROBLEMS. JUST TAKE ONE LOOK AT ANY FACILITY STATE HEALTH DEPARTMENT FILE AND YOU WILL SEE MANY DIFFERENT WAYS ADMINISTRATORS HAVE FILLED OUT THE POC AND THE MANY DIFFERENT DECISIONS MADE BY DIFFERENT SURVEYORS AS TO THEIR ACCEPTANCE.

B. THERE MUST BE A LIMIT TO THE NUMBER OF POCS AN ADMINISTRATOR CAN SUBMIT BEFORE BEING PENALIZED. THIS SUBMISSION, RETURN, SUBMISSION, RETURN LEADS TO ALOT OF WASTED TIME WHILE RESIDENTS ARE AT RISK.

C. THERE MUST BE MORE THAN ONE FOLLOW-UP VISIT TO A FACILITY FOUND OUT OF COMPLIANCE WITH CARE EVEN IF THE FIRST FOLLOW-UP DEMONSTRATES FULL COMPLIANCE. CONSUMERS IN NEW YORK STATE HAVE SEEN MANY INSTANCES WHERE A FACILITY WAS OUT OF COMPLIANCE AT ITS ANNUAL INSPECTION, IN COMPLIANCE AT THE FOLLOW-UP VISIT, AND OUT OF COMPLIANCE SOON AFTER THE FOLLOW-UP VISIT. THIS LACK OF COMPLIANCE THEN TENDS TO REMAIN UNTIL THE STATE'S NEXT ANNUAL VISIT. IT IS INTERESTING THAT EVEN THOUGH SUCH A FACILITY KNOWS WHEN THE STATE WILL COME IN FOR THE ANNUAL VISIT, IT IS STILL FOUND TO BE OUT OF COMPLIANCE. HOW MUCH MORE WOULD THE STATE SEE IF ITS VISITS WERE REALLY A SURPRISE AND IF THE STATE CARRIED OUT MORE FOLLOW-UP VISITS.

4. FEDERAL REGULATIONS MUST CLEARLY DEFINE WORDS SUCH AS "HAZARD TO HEALTH AND SAFETY", "DANGEROUS TO THE LIFE AND SAFETY", ETC. STATES NEED A WORKABLE DEFINITION OF THESE TERMS TO BE ABLE TO USE ITS ENFORCEMENT PROCEDURES EFFECTIVELY.

5. MORE TRAINING IN INVESTIGATORY TECHNIQUES, WITNESS PREPARATION AND THE LEGAL SYSTEM MUST BE GIVEN TO ALL SURVEYORS. NHCC BELIEVES THAT IF MORE TRAINING IN THESE AREAS WERE GIVEN, MORE STATE ACTION WOULD BE TAKEN AND MORE CASES COULD BE WON. THE TIME NOW SPENT BY THE LEGAL STAFF OF THE HEALTH DEPARTMENT IN REVIEWING WRITTEN SURVEYOR'S REPORTS AND HEALTH DEPARTMENT STAFF RECOMMENDATIONS WOULD BE CUT DOWN, THEREBY REDUCING THE LENGTH OF TIME FOR EFFECTIVE ACTION.

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IN ADDITION TO THE RECOMMENDATIONS DISCUSSED ABOVE, NHCC WOULD LIKE TO BRIEFLY STATE A NUMBER OF OTHER CONCLUSIONS WITH WHICH IT IS ALSO IN STRONG AGREEMENT WITH: NURSE AIDE TRAINING; DISALLOWANCE OF MEDICAID DISCRIMINATION; ACCESS TO NURSING HOMES FOR CONSUMERS AND THEIR ADVOCATES; CONSUMER ACCESS TO FACILITY COST REPORTS; AND ACCESS TO ONE'S OWN MEDICAL RECORDS.

IN NEW YORK STATE, REQUIREMENTS FOR THE TRAINING OF NURSING HOME AIDES, THE STAFF THAT PROVIDES 90% OF THE "HANDS-ON" CARE, IS VAGUE EVEN THOUGH THERE IS EVIDENCE THAT TRAINING CUTS DOWN ON AIDE TURNOVER AND PATIENT ABUSE. MEDICAID DISCRIMINATION LIMITS ACCESS TO OUR STATE'S NURSING HOMES FOR THE POOREST OF OUR FRAIL ELDERLY AND ENCOURAGES A BACKUP OF MEDICAID LONG-TERM CARE PATIENTS IN THE HOSPITALS.

ACCESS TO NURSING HOMES AND COST REPORTS WOULD ALLOW ADVOCATES TO HOLD BOTH FACILITIES AND THE HEALTH DEPARTMENT MORE ACCOUNTABLE AND WITH ACCESS TO ONE'S OWN RECORDS, NURSING HOME RESIDENTS AND/OR THEIR FAMILIES WOULD BE ABLE TO PARTICIPATE MORE IN THE PLAN OF CARE AND WOULD BE ABLE TO QUESTION CARE GIVERS MORE ABOUT THEIR TREATMENT; THEY CAN BE BETTER PROTECT THEMSELVES.

IN CONCLUSION, NHCC URGES CONGRESS TO TAKE STEPS TO ENCOURAGE HCFA TO DELAY ITS IMPLEMENTATION OF ITS MANDATED SURVEILLANCE PROCESS UNTIL IT HAS BEEN MADE MORE EFFECTIVE, AND TO IMPLEMENT THE COMMITTEE'S SUGGESTIONS, AS WELL AS TO MAKE SURE THAT HCFA HAS THE FUNDS IT NEEDS TO CARE FOR OUR NATION'S FRAIL ELDERLY.

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Mr. BIAGGI. Thank you very much for your valued testimony. Clearly, surveillance inspection is important, but I think the unfortunate part of it is the people in the business know the exact limitation on the part of the Government on their ability to do that, and that is why it is important to provide some additional funding and place greater emphasis on it—with surprise visits. I mean, an announced visit is cosmetic at best.

Felix Casimir, Volunteer Ombudsman; Louis Krieger, legislative director of the New York Chapter of AARP; and Nellie Peissachowitz, board member, FRIA, that is the Friends and Relatives of Institutionalized Aging.

Mr. Casimir.

STATEMENT OF FELIX CASIMIR

Mr. CASIMIR. My deep gratitude to Congressman Biaggi's subcommittee for the insight and wisdom in bringing together this august body for a very humane purpose.

My name is Felix Casimir. I have been a volunteer ombudsman with the New York City Long Term Care Ombudsman Program since February 1984. The program is part of the Community Council of Greater New York, and funded through title 3 money of the Older American Act from the State office on aging, and the New York City Department for the Aging. I serve the 160 residents of Cabs Nursing Home in the Bedford-Stuyvesant community of Brooklyn. I visit on Saturdays for approximately 4 hours each week, which amounts to some 208 hours of service each year.

I am a social worker by profession, and have a deep personal as well as professional commitment in improving and monitoring the quality of care provided to elderly residents of long-term care institutions in my community. During the past 2 years, I have assisted residents to resolve numerous problems, such as medication adjustments, food preferences, medical consults, and room disagreements.

I have found facility staff to be cooperative and sensitive to resolving resident's concerns. I would like you to know that some of my colleagues, all volunteer ombudspersons, have handled the cases including such problems as loss of personal values, lack of rehabilitation services, medical mistreatment, and community discharge.

I was especially heartened to see, after reviewing the Institute of Medicine recommendations, that the emphasis was placed on ensuring the quality of life and care provided by nursing home residents. As an ombudsperson, I believe that a strong indication of the quality of care provided within facilities, is the quality of the staff who provide the care directly to the residents.

I fully support the Institute's recommendations 3-7B, which specifies that all nurses aides complete preservice training from a State provided training program in a State accredited institution. I would like to broaden the recommendation by including that staff at all levels within the long-term care facility obtain proper credentials or education in the field of geratology, which will help prepare and sensitize them to the special needs of the elderly institutionalized resident.

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Additional opportunities for geratological training and education must also be available at inservice sessions for all facility staff. Facility staff must also be better trained to accommodate those residents who are not only physically disabled and mentally impaired. As a social worker, I can fully appreciate the need for the Institute's recommendation 3-9, which calls for every facility of 100 or more beds to employ at least one full-time social worker with a bachelor's-level education. But I also believe that in order to more successfully address the needs of an increasing caseload of frail and mentally impaired residents, we must require more special skills and advance educational credentials from our health care professionals. I would suggest that such facilities employ more than one social worker who has attained at least a master's degree in social work education.

The institute's recommendation 3-4 reaffirms the fact that environmental factors significantly effect the promotion and maintenance of the quality of life for nursing home residents. Facilities must be physically equipped so that they enhance and maximize independent living for all residents.

Nursing homes should be designed to provide sufficient room and space to afford individual privacy and accommodate a host of recreational and community activities. Such essential features as smoothly functioning elevators, plentiful and accessible grab bars, or adapted eating devices, are all part and parcel of promoting the independence, dignity, and safety for nursing home residents.

Most importantly, civil and individual rights of nursing home residents should not be compromised just because those persons now reside within an institution. In particular, I support the right of the resident to inspect his or her own medical or social records upon request as stated in the Institute's recommendation 3-6D. I also believe that it is fundamentally necessary for trained ombudspersons to be able to request and obtain such access to records for those residents who want us to review their records.

The recommendation 6-2 is absolutely essential in facilitating the investigation and resolution process of resident's specific problems or complaints by ombudspersons in nursing home facilities.

New York State Certified Ombudspersons have been granted access to all nursing home facilities since 1980. This has enabled us to serve residents in a wide variety of nursing home facilities. There are a number of States which do not permit ombudspersons such unqualified access.

Mr. BIAGGI. You have 30 seconds, Mr. Casimir.

Mr. CASIMIR. I support specifically the recommendation 3-7F, which guarantees access for all certified and trained ombudspersons, and endorse the right of facility access to educational and community organizations which provide advocacy help for social services for nursing home residents as stated in the Institute's recommendation 3-5B.

I also support the Institute of Medicine's recommendation 3-7E, which would require all facilities to develop and implement a volatile plan for maximum resident participation in the decisionmaking process. As the Institute of Medicine has recommended, section 4-5 and 4-7, I believe that Federal regulations should require a new surveillance process for all facilities that would rely heavily

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on face-to-face interviews with specially trained surveyors and several residents within the facility.

Ombudspersons and family members should also have a formal opportunity to share their experiences with surveyors. Such a survey should provide invaluable information to surveyors who wish to gain a more representative and varied picture.

Mr. BIAGGI. Mr. Casimir, your time has expired.

The next member of the panel would be Mr. Krieger, but we will interrupt for 1 or 2 minutes. We have the pleasure of having with us to join us for a moment or two, the borough president of the Borough of Manhattan, David Dinkins.

STATEMENT OF DAVID DINKINS, PRESIDENT, BOROUGH OF MANHATTAN

Mr. DINKINS. Thank you very much.

I am pleased to join with my good friend Mario Biaggi and Tom Manton. I am delighted to see you, I used to see him often in the city council during a long term as city clerk, when the city clerk was also the clerk of the city council. So, I am pleased to note that the Congressman Manton is the same fine legislator that he was as a member of our city council.

Mario Biaggi and I are friends of many, many years, and I am just delighted to join him and the members of the House Select Committee on Aging to welcome you a bit belatedly to this hearing on "Nursing Home Residents, a 1986 Assessment" that is sponsored by the Subcomittee On Human Services.

Today is National Nursing Home Residents Recognition Day, which is an event that I have proclaimed here in the Borough of Manhattan. There are over 1 million Americans who live in nursing homes including almost 100,000 in New York State and 37,000 in New York City. It is far too often that the elderly population is institutionalized and overlooked by the community and by public policymakers.

Many of the residents of nursing homes continue to be vital members of our society. Care for our seniors in nursing homes is an important and significant aspect of life families, the community, and Government. I am pleased, Congressman, that you are holding this significant hearing here, and I look forward to working with you to implement the resulting recommendations.

Thank you so much

Mr. BIAGGI. Thank you, Borough President Dinkins. We know of your concern and cooperation as Borough President is critical, especially dealing with many of the areas of our concern at the city level. We have the State and the Federal working together. We have in the past made substantial progress and I am sure it will continue.

Thank you, very much.

Mr. BIAGGI. Mr. Krieger.

STATEMENT OF LOUIS KRIEGER

Mr. KRIEGER. Good afternoon Congressman Biaggi, Congressman Manton, and Borough President Dinkins. I am Lou Krieger, a

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member of the American Association of Retired Persons, and chairman of its New York State Legislative Committee.

On behalf of AARP's 22 million members, of whom nearly 1.8 million live in New York, I am honored to share with you AARP's views on steps needed to improve the lives of nursing home residents. The American Association of Retired Persons applauds the Institute of Medicine's report on improving the quality of care in nursing homes. AARP supports many of the recommendations contained in the report, and urges Congress and the Health Care Financing Administration to implement them by means of statutory and regulatory reform as soon as possible.

We are particularly pleased that the IOM recommends that nursing home surveyors focus on the actual treatment of residents in lieu of paper review of facility capabilities to deliver care. Although conditions in the nursing home industry have improved, there is still an urgent need to better protect nursing home residents.

However, we are concerned that first, ACFA's new survey instrument, patient care and services PAC's, is not strong and reliable enough to be a useful tool. Secondly, ACFA has not provided adequate training for State surveyors, who must use this new tool. Third, States will not be able to carry out their increased roles in assuring nursing home compliance with new and more stringent standards, unless ACFA provides essential training, guidance, funding, and oversight of State reviews. And we believe that where a State has more stringent standards than the Federal Government, the Federal Government should grant the waiver.

Fourth, the States will need strengthened statutory authority, guidance and incentives to improve their enforcement of required standards, procedures and conditions of participation. Existing procedures and standards in New York State for assuring that nursing home residents receive quality care in a manner that preserves individual dignity and human rights are in many respects stronger than existing and proposed Federal standards.

We believe that Federal rules should recognize and support New York's efforts in this area: Our State reviews, more Federal training, and financial report from ACFA to form up to our standards. Unless Congress takes the lead, we are concerned that ACFA's pension for deregulation will result in inaction and failure to implement the IOM report recommendations.

AARP applauds congressional proposals to implement by statute many of the IOM recommendations, and looks forward to working with Members of Congress to improve the welfare of our 1.5 million nursing home residents of whom 100,000 are in New York State.

Thank you.

[The prepared statement of Mr. Krieger follows:]

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PREPARED STATEMENT OF LOU KRIEGER, MEMBER, STATE LEGISLATIVE COMMITTEE, AMERICAN ASSOCIATION OF RETIRED PERSONS

Congressman Biaggi and members of the committee, I am Lou Krieger, Chairman of the New York State Legislative Committee for the American Association of Retired Persons. On behalf of AARP's 22 million members, of whom nearly two million live in New York, I am honored to be here to discuss the Institute of Medicine's (I.O.M.) report on nursing homes.

Introduction

The AARP believes that the I.O.M's Nursing Home Study Committee members and staff performed an outstanding public service to the more than one million older Americans residing in nursing homes. We believe both the deliberation process by which the report was developed and the content of the report deserves high praise.

AARP strongly concurs with many of the recommended actions put forth in the I.O.M. report. The report is a step in the right direction towards more effective protection of residents' rights to quality care, personal dignity, and human rights. We are especially pleased that the report stresses the need to focus on the treatment of residents during nursing home surveys. We agree that the present reliance on paper reviews forms an inadequate and misleading basis for determining the quality of nursing home care.

Needed Recommendations

Among the many recommendations with which we concur, AARP specifically supports the following:

1. The existing distinction between standards and conditions of participation for SNFs and ICFs should be eliminated. A single, consolidated standard based on SNF requirements should be the basis for both Medicare and Medicaid certification and review.

2. Existing SNF conditions and standards should be based on an evaluation of services provided as well as direct observation of residents' quality of life, care, and assessment.

3. Certified facilities should have a registered nurse on duty at all times and nurses aides must complete an approved training program.

4. Beneficiary rights should be enhanced and made an integral part of nursing home operations.

5. Nursing homes may not discriminate against applicants for admission or against residents on the basis of their source of payment.

6. Ombudsmen and representatives of community agencies must have access to nursing homes.

7. Surveys should be surprise events, should be outcome and resident oriented, be based on valid samples, and should focus on key indications of quality of care. Substandard facilities should be targeted for early and comprehensive re-review. Surveys should not be paper reviews but should be based on direct interviews with and observation of residents and staff.

8. HCFA should require states to provide consumers with nursing home inspection and cost reports.

This list of paraphrased recommendations from the I.O.M. report with which we agree is by no means exhaustive. It merely serves to illustrate the point that the I.O.M. report should form the basis for new public policies on nursing homes. AARP hopes the report will provide states with a foundation upon which to build their own nursing home regulation program.

However, we also have some concerns about weaknesses contained in the report.

Areas of Concern

1. The new HCFA survey instrument, PaCS (Patient Care and Services) is, at this point in its development, a much less satisfactory tool for nursing home review than the I.O.M. report indicates. In AARP's view, a great deal of work on PaCS remains to be done before it will be a strong, reliable, and useful survey tool. Moreover, HCFA has not adequately provided for training of surveyors who must soon begin to use this instrument. It is not plausible that all of New York's 800 surveyors will have been properly trained in time to use the new survey. HCFA does not specify criteria for the selection of surveyors. We in New York seek surveyors with relevant skills in observation and taking evidence and we test surveyors to establish their skill as observers. HCFA's national standards should require at least the same degree of skill as the state of New York. We believe that people with nursing and investigative skills make good surveyors and recommend the use of such people for conducting nursing

home surveys.

In addition to HCFA's failure to properly train those who will use the PaCS survey, we in New York believe that the PaCS instrument relies far too heavily on paper reviews and not enough on the actual outcomes of care.

Furthermore, the PaCS requirements for sampling residents would produce far too few cases to allow for valid generalizations in a large nursing home such as we have here in New York. Most of our nursing homes have over one hundred beds. We in New York have far more stringent survey requirements than those required by the PaCS survey.

This raises another serious concern. HCFA has told state agencies to follow the federal format and procedures without exception, or lose federal financial participation. HCFA has been unwilling to coordinate its efforts with those of states with strong enforcement. We strongly recommend that waivers be granted to states with survey methods and enforcement practices that exceed federal requirements.

Thus, while we are pleased that HCFA is at last beginning to develop a uniform national reporting system, the survey instrument procedures and personnel selection and training components of the PaCS system need to be strengthened to meet the existing standards in New York State.

2. Since the I.O.M. recommendations place a heavy burden on the states, we are also concerned that states will not be given the needed support and guidance from HCFA to implement more stringent monitoring and enforcement standards. States need better guidelines and regulations specifying compliance criteria and sanctions; and we need more training and financial support for state surveyors and state nursing home officials.

3. States vary in their statutory authority to impose intermediate sanctions on nursing homes that are chronically out of compliance. Unless the federal government takes the lead to authorize a consistent
set of intermediate sanctions, states that don't have a strong commitment to enforcement are unlikely to take effective action against substandard nursing homes.

4. Most serious of all is our concern that HCFA will not implement the needed reforms specified in the I.O.M. report. HCFA's recent efforts to weaken nursing home regulation is the basis of our concern. It was only because of the Congressionally imposed moratorium on new regulatory proposals for nursing homes and

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strong consumer support that HCFA funded this I.O.M. study. Congress and consumers must continue to prod HCFA to implement the reforms identified by the Institute of Medicine.

Congressional Action

Many of the I.O.M. recommendations require Congressional action. AARP is pleased that legislation has already been proposed to implement some of the necessary statutory changes at the Federal level. The Nursing Home Protection Act of 1986, H.R. 4485, introduced by Senator Pepper includes many of the I.O.M.'s proposals on rights, changes in the survey and certification process and the general administration of nursing homes. The AARP is particularly intrigued by Senator Pepper's proposal to give nursing home residents a private right of action for violation of their residents' rights.

Both Senator Cohen and Congresswoman Snowe of Maine are sponsoring legislation on nursing home patients' rights (H.R. 4279 and S. 2119). Although not identical, these bills make similar proposals to improve and protect nursing home patients' rights. The Association is particularly pleased that nursing home discrimination against Medicare and Medicaid patients is strictly prohibited under these bills.

Senators Heinz and Glenn are working on bills that will improve the administration and coordination of our nation's chronic care system. In addition, the Heinz/Glenn proposals strengthen the enforcement of nursing home standards and strengthen the Ombudsman programs' ability to monitor nursing home care. And, we are particularly pleased that you, Mr. Biaggi are working on legislation intended to strengthen the Ombudsman Program. AARP looks forward to working with you on this important aspect of nursing home reform.

Conclusion

The American Association of Retired Persons supports these efforts to strengthen and improve our nation's continuum of care. These legislative proposals and the report by the distinguished Institute of Medicine represent a new era in the development of nursing home care. There is a growing consensus among patients and providers, regulators and payors about the future direction of nursing home care. AARP is proud to be a leader in that movement.

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Mr. BIAGGI. Thank you, Mr. Krieger.

STATEMENT OF NELLIE PEISSACHOWITZ

Ms. PEISSACHOWITZ. My name is Nellie Peissachowitz. I represent the Friends and Relatives of Institutionalized Aged, one of the first patient and resident advocacy organizations in the State or even the country.

I also represent myself as an advocate for nursing home residents. During the 10 years of my sister's being in a nursing home, I have become intimately familiar with and aware of the multifaceted aspects of nursing home life. There are many things I planned to address, but I think the residents and the other speakers have dealt with them so adequately, it would be redundant to go into it.

So, let me just add a few things. One of the things that is important to remember is that institutional living brings with much loss of independence, and veto power of rights one had when one was a member of the outside community. And, therefore, we feel that it is especially commendable that the committee has been sensitive and focused so strongly on the inclusion of residents in the decision-making process at almost every level.

Their report attests to the sensitivity, concern, understanding, and expertise of the committee. Their recommendations, we hope will be implemented. And one of the biggest problems we have is we have things on the book, regulations that are on paper and that are not being implemented. We hope that this time whatever goes in as a regulation, will with it bring a mechanism to really have successful implementation.

I would like to go back to the topic of training. Training is essential, and it is essential for all levels of staff including the medical. Physicians need to know more about geriatrics. They need to know and be aware and practice what they are supposed to in regard to patient rights. This is a very weak area, and I think that training and education in that area is very important.

I would like to mention that it is the aide who does 80 to 90 percent of the hands-on care in the nursing home, and it is they who are receiving the least training and the least equipment for a very serious and very responsible job. It is they would can set the climate, and who could improve the quality of life considerably.

I would like to read a note that I made of a dream my sister told me once. I think it speaks for itself, the feelings and the wishes are expressed in a better way than I think an outsider or myself could. She was telling me,

> I had a strange dream last night. I was in the room with all the aides, and I said "my dear nurses aides, don't forget that we are handicapped but complete human beings with a right to talk. Please before you move us, tell us what you are about to do. We are not pieces of furniture. When you take off the sheet or blanket, it is not a dust cover you are recovering from the summer furniture, you are removing it from a live person. When we ask your help, please do it with a friendly face without disparaging remarks. When we ask for the bed pan, we really need it. Do you realize how a person feels as an adult who cannot even toilet herself? Remove the pan in reasonable time, as it is painful to be sitting on the buttocks on a hard surface in addition the hours we have to sit and spend in a wheelchair. If one could only have a wish, it would be to be allowed to get out of the wheelchair and stretch out on the bed for an afternoon break from the torture of sitting in the chair. The rest of the day would be so much easier. And don't do anything we don't ask you to do, especially if we are able to do it ourselves, even if it takes a little longer time. Because it

discourages you any effort to help yourself. Do you realize how it feels for a grown-up who was independent and able to take care of herself and her family to have to beg for every little detail to be done for her? May God save you from this fate. We are deeply thankful for what you do, but don't forget we have our good and bad days like other people, maybe more so because pain rules us and we have no control." I woke up, and I was thinking how nice it would be if one could really talk with each other, thus understand one another better.

There is a recommendation that I think is very important, and that is a national advisory committee, which will design training programs. And on that committee should be and is suggested also, consumers, relatives and people from advocacy organizations. I would like to see a ratio spelled there because we see on so many advisory boards only a token of consumer participation.

The right to view the medical record is one of the most important recommendations in the area of patient rights.

Mr. MANTON. I have the unpleasant chore as acting chairman to say if you are ready to conclude, you have about 30 seconds.

Ms. PEISSACHOWITZ. I just want to say that in general we are really grateful that this report came out the way it did. It really exceeded our expectations, and we hope that Congress will continue its effort to implement and to see to it that it gets accepted by an administration who has really denied progress.

Mr. MANTON. Thank you very much.

[The prepared statement of Mr. Peissachowitz follows:]

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PREPARED STATEMENT OF NELLIE PEISSACHOWITZ, BOARD MEMBER,
FRIENDS AND RELATIVES OF INSTITUTIONALIZED AGING

My name is Nelly Peissachowitz, I represent FRIA, Friends and Relatives of Institutionalized Aged as well as myself as a relative and advocate for a Nursing Home Resident. During the 10 years of my sisters being a resident/patient in a Nursing Home I have become intimately familiar with and aware of the multi-faceted aspects of Nursing Home life.

I am grateful for the opportunity to testify at this important hearing about the report of the Institute of Medicine regarding Nursing Home Regulations.

The report which was two years in it's development is an outstanding document , it attests to the sensitivity , concern, understanding and expertise of the Committee in regard to the complex problems. The recommendations suggest that a stronger Federal role is essential- it is our hope that the conclusions and recommendations of the committee will be heeded and forcefully implemented.

We applaud and strongly support the recommendations which attest to thoughtful analysis and committment to include the resident , the consumer and advocate in a wide arena.

Institutional living brings with it much loss of independence and vote power, of rights one had and took for granted as member of the outside community.

Especially commendable is the emphasis on Q ALITY OF LIFE and the approach that-" the criteria should address residents needs and the effects of care on residents and on the performance of a facility in providing care rather than on its capability to perform."

3-5 requires a new condition of participation based on Quality of care

" each resident is to receive high quality care to meet individual physical, mental and psychosocial needs-"

As with all other regulations there will need to be specificity and legally enforceable language.

3-1 We applaud the recommendation for unification of standards for SNF and ICF levels. " The regulatory distinction between SNF and ICF should be abolished" While currently there is the requirement of 24 hour 7 days a week presence of a RN in the SNF ,the ICF only requires this presence in daytime. Night is the time of many serious crisis requiring the competence of a trained nurse, available on the premises.

We urge that the recommendation contained in the suggested regulations be implemented -as a new condition of participation Patient ASSESMENT mandating the special training of the RN for performing, monitoring and supervising this task.

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Training

We are strongly supporting the idea of more specific, extended and universally applicable training.

The training of staff on all levels is of paramount importance, including the medical staff who often do not have updated geriatic information and only too frequently are unaware of the PATIENT's RIGHTS.

80-90% of all "hands on" care is provided by Nurses Aides and Orderlies. They receive varying degrees and intensity of training which differs among the States as well as the individual facilities.

We here in New York are actively involved to get mandatory comprehensive training legislated.

The Aides who receives little training and preparation for their crucial role is the one who has the most intimate contact with the resident/patient and could be the one to establish a climate of caring , of individual concern and attention so necessary for the quality of life of the residents.

In this connection I would like to read to you the dream of my sister, a paraplegic , resident for almost 10 years in Nursing Homes.

I wrote down in her own words as she recounted the dream to me. I think it speaks for itself -the feelings and wishes expressed encompass more than I could possibly present.

I had a strange dream la st night
I was in a room with all the aides and said:

"My dear Nurses' Aides: Please don't forget that we are handicapped but complete as human beings with a right to talk. Please, before you move us, tell us what you are about to do. We are not pieces of furniture. When you take off the sheet or blanket over the lap, it is not a dust cover you are removing from summer furniture -- you are removing it from a live person. When we ask you for help, please do it with a friendly face without disparaging remarks. When we ask for the bed pan, we really need it. Do you realize how a person feels as an adult who cannot even toilet herself? Remove the pan in reasonable time as it is painful on the buttocks to sit on a hard surface in addition to the hours we have to spend sitting in a wheelchair.

"If one could make a wish, it would be to be allowed to get out of the wheelchair and stretch out on the bed for an afternoon break from the torture of sitting in the wheelchair. The rest of the day would be so much easier.

"Please don't do anything we don't ask you to do -- especially if we are able to do it ourselves, even if it takes a little more time -- because it discourages any effort to help ourselves.

"Do you realize how it feels for a grownup who was independent and able to take care of herself and her family to have to beg for every little detail to be done for her? May God save you from this experience!

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"We are deeply thankful for what you do -- but don't forget -- we have our good and bad days like other people, maybe more so because the pain rules us and we have no control."

I woke up. I was thinking how nice it would be if one could really talk with each other and, thus, understand each other better.

For many workers it is just a job. To others it is more, a committment , dedication to a human experience.

Many Aides have commented that they wish they had a better understanding on how to approach the confused, the the depressed, the agitated, the non-communicative person. There is frustration and little job satisfaction if you do not know and feel inadequate. Many resent the fact that they are the ones who are expected to orient , teach the new person when they themselves do not feel adequate.

6-2 It should be a federal responsibility to set standards . The establishment af a statutatory National advisory council is an excellent concept. We feel specifics are needed regarding the ratio of participants, professionals, consumers ,advocates, family members.

For training to be meaningful and contribute to the quality of life there needs to be a universal curriculum . The expertise of professionals will be enhanced by the input of those who know first hand , they are uniquely equipped to identify program needs and priorities- the consumer, family members and residents themselves.

3-6 In the area of Patient Rights it is important that they be expanded and above all implemented. There now are specific rights spelled out - but they ate in many instances "inplace" on paper only. To be involved in one's treatment plan, to know the goals and how they might be achieved- the right to be"fully informed"- to refuse treatment or medication. Such refusal of course requires careful explanation of the possible consequences ,but it is right that must be respected. Only too often the Nurse or physician reacts with anger or even threats when a patient refuses or asks for explicit information.

There are many undocumented occurances -such as putting a paralyzed patient into a bath against his/her will- the non-ambulatory person has no way to avoid this- the effect of such episodes is traumatic as it adds to and heightens the feeling of powerlessnes.

We are very much in agreement to have Patient Rights raised to a condition of participation with the new rights standards added.

But most important is the recommendation 3-6 to give the right to access of one's own medical and social record.

Too many judgements so far have been based on the "record"-the written statements of staff.. They not always are congruent with reality of events.

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We here in New York have achieved the right of a resident/patient to have her/his version stated in case of accident or incident. This must be included in the record and copy of the person's statement given to the person or his chosen surrogate. Only too often there is a difference in the alleged causes of the occurance. For example -to mention only one situation:

I recall being confidentially alerted to an entry in the patient's chart by a consultant orthopedist of the facility not only not diagnosing a fracture: "there is no fracture"(the fact that there indeed was a fracture of a finger./ was validated by an outside specialist) but stating " this totally confused patient".. Both statements were wrong. Only because of the insistent pressure of the relative did this statement get amended, i.e. the medical director conceded that labeling the person"totally confused" was incorrect as there were no such findings or diagnoses. Entries such as these are detrimental to the patient they tend to result in pre-judging and prejudicial attitude towards the person.

Failure to be able to review the record is detrimental in instances of complaint of abuse, neglect or mistreatment. Here in New York if a complaint is deemed to be unsubstantiated the case record is expunged. The complainant who is advised of this decision- it currently takes about 1 1/2 years to get this information i- has no way to get a review or hearing on the case. No explanation as to the reasons for that decision is given, other than "lack of credible evidence".An explanation as to the WHY is needed. Were there omissions in the record? The whole area of patient rights and protection needs further study and national standards, including time frames .

3-6 F Another important contribution is 3-6 F which mandates " the right to organize maintain and participate in resident advisory and family councils" Hopefully this will eliminate instances where as it happened an administrater threatened to eliminate the Family Association and falsly claimed that his facility was unique in permitting such an association. It can only be seen as a retaliatory move against a informed active group and their leader.

Survey Timing

Residents and staff know when to expect the annual survey. The following comment was made by a resident:"They must be expecting the inspectors- the windows are being washed-even the screens cleaned- my drawers re-arranged-it is like before the horse show- the horses are being pressed".

Deputy Attorney General for Medicaid Fraud stated on February 6, 1986 "Under the PAC system surveys will continue to be conducted at the same time each year. Time and again our investigators show that Nursing Homes are able to pinpoint the exact time of these inspections and prepare thoroughly. The result is that the Nursing Home observed by the surveyor is not the Nursing Home lived in by patientsthroughout the year. To obtain a true picture of nursing home life surveys must be conducted at varying times throughout the year. The goal of

nursing home inspections should be the assurance of consistentquality care.
not the observation of a well orchestrated performance ." (Underlined by me)
Although fines and sanctionsfor deficiencies and violations are part of existig
regulations-implementation of rules is is lacking. We have documented evidence of
a facility who for 8 years had the same repeated violations. There must be
a system to monitor corrections, to insure the permanent removal of deficiencies
and violations -to stop the chronic violators.Unannounced inspection and a
minimal time-frame is needed

4-2 We applaud the additional standard-surveys indicating key events.
It is our position that not only change in ownership but a change in
executive director- administrator should trigger a complete survey. The standards
of a new administrator or executive director impact on the whole facility
-it may mean changes to the better or the worse

3-7 We welcome the recommendation that..." added to the administration conditions
that would require every facility to develop and implement a plan for regular
resident participation in decision making in the facility's operation and policies
and for presentation of resident concerns"..We would like to see the inclusion
of Family Association or Council representativesin addition to the Resident
Council. It is the family who often speaks for those unable to speak for themse-
selves . the bedbound, the more impaired resident/patient, the one who does not
participate in the resident council. It is the Family Council that can add
valuable information and can be he lpful in decision making . We urge that
this suggestion be accepted by the Committee. I am well aware that there
Family Councils who have been co-opted , are "company Unions"- a situation
we hope to change in the near future.
We have only few differences of opinion regarding the recommendations
let me just mention those

B7 A " We do feel that quarterly staffing reports need to continue in order
to identify those facilities which produce a full compliment of staff at the time
of survey and inspection but then fall back into the pattern of minimal and
inadequate staffing in relation to their residents/patients needs
Regarding SOCIAL WORKER ratio and qualification:
It seems the ratio of loo be ds is high if the social worker is to provide
the full range of his/her skills . more and more needed by a rapidly changing
more frail population. A Social Worker with a Masters Degree and special
education in geriatics or comparable experience is indicated for the complexity
of problems faced by the resident/patients and even staff. Counceling and
effective advocacy is needed. BS worke rs can perform excellently
but the ultimate burden of responsibility including supervision should rest
with the MSW.

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Too often Social Workers in the facilities are assigned other tasks and not always used to the full potential of their skills. It might be helpful to set standards in this area a s well.

To conclude I want to express our pleasure at the suggestion to assess the benefits and cost of single room occupancy. The pt/resident of course should have the choice whether to share or live alone. I recall vividly when during my study of care of the aged in Denmark I noted the privat rooms in all homes. I asked what the criteria for this priviledge were-with great astonishment I was given the answer " do you share your bedroom with someone other than your husband or boyfriend? Why should they-".

Mr. MANTON. That concludes our panel 3, and we will call panel 4, Dr. Nicholas Rango, Eileen Quinlan, R.N., and Tom Spicuzza.

One of the reasons we have been sort of tight on controlling the time is that many of the people that are here have a pretty set schedule of getting to their buses, and we wanted them to hear as many of the panelists as they could. So, you will forgive us for being a little strict on the time.

Our leadoff witness on panel 4 will be Dr. Nicholas Rango.

PANEL FOUR: CONSISTING OF DR. NICHOLAS RANGO, PROFESSOR, BARNARD COLLEGE: EILEEN QUINLAN, R.N., COLUMBIA UNIVERSITY: AND TOM SPICUZZA, SOCIAL WORKER, VILLAGE NURSING HOME

STATEMENT OF DR. NICHOLAS RANGO

Dr. RANGO. My name is Nicholas Rango, and I am at Columbia University, and do research that is focused on the quality of nursing home care in the United States. The first thing I would like to do is to congratulate the Congress for sponsoring the IOM report in the first place. I believe that this represents a very important victory that all of you are responsible for, and had this not gone through, one can only imagine the effects of the very ill-advised attempts by the administration to deregulate the nursing home industry.

I think that there is also cause to congratulate the advocacy groups, particularly the National Citizens Coalition for Nursing Home Reform that brought this to bear.

Honorable Congressmen, I would like to address myself to that portion of the IOM report that addresses the question of resident involvement, family involvement, community involvement, and the Ombudsman Programs in determining the quality of nursing home care. This report, I think, highlights appropriately that one can invest a great deal of expertise and money in creating the quality of professional care, but if you do not have these other essential components as part of your total package, than indeed the overall quality of institutional care will be weakened.

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The second suggestion that I have goes to some of the language that is used with respect to this IOM report. I think a lot of us are very concerned about some of the undesirable consequences of pushing too hard on language that focuses on quote, "consumer participation," and, "consumer advocacy." I understand where this language came from, it comes from the history of the advocacy movement, but indeed when one is talking about nursing home care in the United States, it is a myth to refer to nursing home care in terms of consumer soverignty.

It may be much more politically advisable for us to get back to the whole question of defining nursing home rights, not in terms of consumer rights but in terms of individual rights. That seems to me to get Congress much more in line with establishing a nonideological, nonpartisan basis for establishing the kind of congressional oversight that nursing homes in general and nursing home residents in particular need.

I would like to emphasize that if you use individual rights when referring to nursing home care, it appeals I think to the long-established American tradition of trying to get at something that is frankly not a top political issue.

One last point on the whole question of getting these kinds of reports and issues before the American public. Myself as a physician, and those of us that are doing research in nursing homes often times tell different audiences that each of us might be in a nursing home, each of our parents may be in a nursing home, our wives may be in a nursing home. If one reaches the age of 80, one has a 20-percent chance of having a dementing illness.

So, unlike other minorities that we might be addressing in terms of quality of care, this one might affect us very, very directly in our lives. And I don't think that that has been sufficiently emphasized before the American public so that they would understand what is in it for them in increasing the quality of care in nursing homes in the United States.

Just a few final comments that I want to make about the report itself. I support all of the recommendations that go toward strengthening the Federal leadership role with respect to the Ombudsman Program. Again, this is not to blame one party or the other, but there has in fact been a retreat by the Federal Government over the last 5 or 6 years. You gentlemen represent the return back to a leadership role for the Federal Government. I want to not only congratulate you, but urge that you continue in that very, very fine work.

When this report talks about the role of the State Ombudsman Program, however, and talks about an annual budget of $100,000 per State, plus additional amounts based on the number of nursing home residents in the State, I think we are whistling Dixie. This kind of money is only a token effort. It may have the very harmful effect of giving us a false sense of security in thinking that we are in fact funding strong Ombudsman Programs. You cannot do it in any State, in my judgement, for this amount. And I would urge the Congress to consider whether that amount, even in this time of fiscal stringency, represents an appropriate response.

One last comment, and then I will be through. This report is silent, but I hope your congressional committee, and indeed the

Congress as a whole, will not overlook one very, very important area of nursing home care. And that is the whole are of termination of care. All these issues are now coming to a head. You all are familiar with the *Conway* case, which was just decided by the New Jersey Supreme Court. Other cases are quickly coming to the courts in other States.

We are in an era where we have delivered human beings to an era in which hi-tech medical interventions can prolong their lives. Ethics has not caught up. We need much more attention at both substantive and procedural safeguards to decide whether and how the decision to terminate care of the nursing home resident should be undertaken. And I would urge your committee, and the Congress as a whole, not to overlook this very important area that is just on the horizon in nursing home care.

Thank you for inviting me.

Mr. MANTON. Thank you very much, Doctor.

STATEMENT OF EILEEN QUINLAN:

Ms. QUINLAN. My name is Eileen Quinlan. I would like to thank the Subcommittee on Human Services for their invitation to speak at this hearing on quality of life for residents in nursing homes on National Nursing Home Residents Day. I am here today because I am a nurse. I am currently the director of the Adult Geriatric Nurse Practitioner Program at Columbia University. In the past, I have worked at all levels of nursing staff: nurse's aide, LPN, R.N., geriatric nurse practitioner and consultant to nursing home administration. I have a rather strong personal and professional conviction that based on knowledge and experience this conviction holds that the outstanding and overall need of residents in facilities being described here is excellence in nursing care. True, they do need the attention of a physician, or the assistance of a social worker, dietician, or physical therapist. But on a 24-hour basis, it is the need for attentive, knowledgeable and primary nursing care which dictated the resident's placement in a nursing home in the first place.

Both this subcommittee's invitation and the recently released report on quality of life in nursing homes published by the Institute of Medicine, acknowledges nursing's role in our Nation's nursing homes. I would like at this point to applaud the members of the Committee on Nursing Home Regulation for an outstanding report. It was an enormous undertaking. The plethora of problems were well studied, understood and given reasonable recommendations. Of course, taking these recommendations and putting them into regulation and practice is the next giant step. I am most pleased as a nurse, advocate, and friend of residents in nursing homes, that the report looks beyond the adequate care and the "safe facility," quote/unquote, to define in assessing quality of care and at least some aspects of quality of life.

When one looks at the evolution of this report with the controversy in the early 1980's on the deregulation of the nursing home industry, and the demographic projections for the year 2000, this report provides a foundation for the future of the nursing home industry. Big business is what it has become. It is a service industry;

serving the most frail and vilnerable in our population. Regulation in essential. I was surprised to learn in this report that 80 percent of all certified beds are in homes operated on a for-profit basis. Prior to 1960 nursing homes were essentially unregulated, governed almost entirely by market forces. The regulations enacted in 1975 have basically remained unchanged. I have worked in nursing homes in several States, and have been amazed at how the regulations are administered and enforced so differently in each State, and yet the Federal Government is only able to look behind the scene in less than 3 percent of all facilities. The Federal Government must take a lead in regulation as many States are not. The concept of the standard survey using key indications of quality of resident care is not new, but a system which needs to be refined and promulgated. I endorse the fact that the standard survey would include interviewing residents and staff, rather than 2 days of shuffling papers.

I was amazed when reading this report to learn of the absolute lack of data on nursing homes and residents. A system to obtain standardized date is essential. The Federal Government must operationalize the definition of reasonable cost, relying on individual State Medicaid reimbursements has failed. Alternatives and long-term care must be funded. I am familiar with the skilled nursing facility in New York City that after classification of its residents found that well over 30 percent of them actually do not need skilled nursing care, but these residents have, or had, no other alternatives than institutionalization.

Over the past 15 years when I expressed my interest in gerontology, people are amazed or horrified. It is the residents with whom I work that make my job so rewarding, and yet, less than 2,000 out of a total of 1.4 million nurses are certified in gerontoiogical nursing. It is not an arena for prestige, power, or economic achievement, however, over the past decade I have seen the stone start to gather moss. The literature is filled with studies looking at the attitude and behavior of health providers toward the elderly. Ageism permeates society, even among the old themselves. Thus, a positive attitude toward aging must be fostered from childhood on. The IOM report recommendation that such attitudes be nurtured by sources within the industry and education/professional institutions associated with it has been successfully demonstrated, for example, the teaching nursing homes. The findings of these various demonstration projects will soon be finalized, giving direction for the future.

The IOM report further recommends preservice training for nurse's aides. I see this recommendation as a good beginning, but would like to see also on-going education for not only nurses aides, but all staff. The quality of life to all of us is intimately related to our interpersonal relationships. For the nursing home residents, the majority if not all of their relationships are with staff, primarily nurse's aides. If we do not attract, train, and motivate nursing home personnel, all the rest of this business is for naught. I heartily endorse the IOM report recommendation that an RN with appropriate training be responsible for the assessment of each resident. As I stated earlier, residents are in nursing homes because of their

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intense nursing needs. The nursing staff should be and need to be the primary care provider.

One last thought. I have spent many hours with residents discussing the joys and sorrows of roommates. Other than relationships with staff and food, I can think of no other factor that has greater impact on quality of life. I urge HCFA to commission a study of the cost and benefits of single room occupancy rooms compared to multiple occupancy rooms.

Thank you.

Mr. BIAGGI. Thank you, Ms. Quinlan.

I might comment that 10 years ago we didn't have a single chair in gerontology in this country. Now we have several. So, the focus wasn't on geriatrics, and that is why we didn't have too many nurses. I think you will find more and more as there is greater focus. And it is important that we maintain that focus.

Tom Spicuzza.

STATEMENT OF TOM SPICUZZA

Mr. SPICUZZA. Thank you.

My name is Tom Spicuzza, and I am the director of social services at the Village Nursing Home, a 200-bed skilled nursing facility located in lower Manhattan. The perspective of my comments on the Institute of Medicine's study on the quality of life in nursing homes is, therefore, that of an employee of a nursing home.

I have not read the entire study, but judging from the summary of findings that was presented to me, it seems an important step forward in addressing the issues of care in nursing homes. Really for the first time we have a national perspective on the quality of care in nursing homes that can serve as a foundation for a national policy on the long-term care of our elderly. Until now, the most comprehensive study of the standards of nursing home care in this country was a 1974 report by the Subcommittee on Long-Term Care of the U.S. Senate Special Committee on Aging.

That report, entitled, "Nursing Home Care In The United States: Failure In Public Policy," estimated that roughly half of our Nation's nursing homes are substandard. And it is important to keep in mind that this earlier study focused on physical and safety standards, not on the perspectives of residents regarding the quality of their lives.

Unlike hospitals and other health care facilities, nursing homes have historically been characterized by a lack of governmental interference. Fortunately, this has changed somewhat in the past several years as a result of national awareness of the problems. In fact, nursing home care has become a significant and even passionate social issue, and State governments have responded to public concern with regulations.

As an employee of a nursing home, I regard the governmental regulations of this industry as essential to promoting and protecting the interests and rights of nursing home residents. In fact, more effective Government regulations and a more resident oriented approach to nursing home inspections is needed to improve the quality of care in our nursing homes.

The report also reminds us that one of the most serious problems in nursing home care today is related to staffing patterns. Only 5 percent of nursing home employees are registered nurses, and another 6 percent are licensed practical nurses. On an average, there are just over three R.N.'s and four LPN's per 100 patients. Since the residents are cared for on a 24-hour basis, 7 days a week, while a full-time employee averages 33 hours per week, the real numbers are more like 1.5 licensed nursing personnel per 100 patients.

With so few licensed nurses on the premises, it is understandable that aides bear the brunt of patient care. Ninety percent of direct patient care is delivered by nurse's aides who are not required by law to have any formal training or education. Most are unskilled, untrained, and very low paid. Few jobs are as difficult as a nurse's aides, so it is understandable that the personnel turnover in nursing homes is phenomenal, 75 percent a year is estimated.

The study points out both the need for staff training and the development of nursing home care givers, and the need for a reimbursement system that will make adequate staffing possible. The report also emphasizes the importance of community interest and involvement in nursing homes. Community boards, neighborhood associations, local civic groups, and private citizens should participate in advisory councils to nursing homes, both supporting and monitoring the care they provide. Just as the quality of education in your neighborhood school should be of interest to you, so should the quality of care in your local nursing homes. Relationships between communities and nursing homes enhance the dignity of both, and hopefully can translate into more humane and resident oriented care. A review of demographic and population projections show that there will be more people residing in nursing homes over the next 10 to 20 years.

Nursing homes are important components in the continuum of care for our elderly. They are not going to be replaced by an expansion of community supports for older persons. Therefore, an organized approach to improving care in nursing homes is essential, including the implementation of the recommendations in this study; especially the elevation of resident's rights as a condition of participation.

Thank you for your attention.

Mr. BIAGGI. I want to thank each and every one of you for your contribution.

I wish I had time to question you. If you have a few minutes to remain after the meeting, I would like to chat with you.

I said if we had some time we would permit 1 minute for anyone else who would like to speak. We have 10 minutes, so if anyone would like to make a statement or ask a question?

[No response.]

Mr. BIAGGI. There being none, thank you very much for your patience and your presence.

The hearing is adjourned.

[Whereupon, at 3:50 p.m., the hearing was adjourned.]

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APPENDIX

The Hackensack, NJ Record, 10/14/85

Opinion

Nursing-home sleuths

Investigators are needed to watch out for bad guys

By Bruce Locklin and Gale Scott

For two years the Institute of Medicine has been commissioning research papers for the federal government on how to improve the nation's nursing homes. In the piles of words and statistics, a conclusion jumps out: Bad nursing home operators will continue to neglect patients until they become convinced that government has a system in place that will uncover neglect — and, until punishments are stiff enough that no one wants to face them.

The bad guys have to know that they'll get caught and punished severely. But in New Jersey and most of the nation no one is actively chasing them.

The traditional approach to nursing-home enforcement relies on inspectors, people trained in measuring a home against established standards. There are several types of inspectors: nurses, nutritionists, sanitarians. They're visitors with checklists. They usually can determine if a home is complying with regulations, but they don't have any training in collecting evidence of wrongdoing. They've never been instructed on how to find or interview witnesses.

Inspectors simply don't have the tools to cope with a corrupt nursing-home operator who fakes records and intimidates staff and patients.

New Jersey's Health Commissioner J. Richard Goldstein knows that his troops are not up to the task of building cases against bad homes.

"We are not in the testimony-taking business," Goldstein said in an interview. "We are in the direct-inspecting business."

What New Jersey and most other states need is an effective investigating agency that will catch enough bad guys to scare the hell out of the rest.

Referring nursing home cases to existing prosecuting agencies doesn't work. Jack Fay, New Jersey's former nursing-home ombudsman, tried unsuccessfully for years to get county prosecutors excited about neglect- and-abuse cases. The prosecutors were polite but not really interested, and Fay became convinced that they saw their duty as chasing "real criminals" — murderers, thieves, and the rest.

The enforcement vacuum in nursing homes across the country is astounding, particularly because it's easy to prove that a bad nursing home is a bad nursing home.

The practical experience of investigating the two Bel Air Manor nursing homes in New Jersey for The Record has given us some insight into what it takes to expose nursing home wrongdoing.

We're not nursing home experts or policy planners. But as reporters who spent seven months building evidence of nursing-home neglect, we think we may have found a methodology that any state could use to clean up its nursing homes and make sure they stay cleaned up.

The approach we're suggesting is similar to what the Justice Department did several years ago, when it decided to pursue mob figures with the strike-force concept, setting up an agency designed to go out and find evidence.

Each state could create a nursing-home strike force, a small, mobile team that includes two investigators.

This investigative unit could be part of any one of several existing agencies: the health department, Medicaid fraud unit, attorney general's staff, or ombudsman's office. It should be headed by a lawyer with prosecutorial experience. The staff size could be modest. A minimum would be two investigators and two nurses.

Here's an outline of how such an agency could operate, a three-step process for investigating nursing homes.

● Trigger. There should be a low threshold for deciding to check out a nursing home to see if it merits investigation. An initial check could be triggered when a home is found to have significant deficiencies on annual inspection. An investigation also could be triggered by a decision to repeat complaints to the health department or the state licensing agency.

● Decision. The first step should be to have a team member, a nurse, get a job at the home as an aide or orderly. That's usually easy, because nursing homes tend to have a rapid turnover in aides and orderlies — particularly bad nursing homes.

If the nurse finds no serious, systemic problems, the investigation ends there. If she does find problems, the investigation goes to the next stage.

The undercover nurse isn't gathering evidence. Three days' observation won't mean much in court. The nurse's assignment is simply to flash a green or red light.

It won't take more than a few days for the nurse to know what's up. Bad nursing homes have bad policies and procedures that are easily detected from the inside. If one aide routinely has to feed 15 patients, management has built-in neglect.

● Investigate. The next step, one not currently used by health departments, is to look for witnesses outside the nursing home. As we found at the Bel Air Manors, some of the best nurses and aides get fed up and move on to better nursing homes.

A pervasively bad nursing home spins off many potential witnesses. Investigators find them by tapping into the employee grapevine.

Medicaid field people can help, because they get into nursing homes more frequently than any other officials, often seeing old employees from one home show up at another. Good health-care workers quit bad homes and land at good ones nearby.

If the suspected nursing home is indeed pervasively bad, investigators should be able to find many witnesses with firsthand knowledge who can testify about seeing systemic neglect over an extended period of time. That's the type of solid evidence that can get licenses revoked or criminal indictments.

As elemental as this technique is, it's not used by state health departments. Their "investigations" are limited to recording what inspectors see on the days they visit.

This strike-force approach can be effective, because many potential witnesses are eager to cooperate. Good health-care professionals are well-motivated people. They want to see bad nursing homes cleaned up.

But government is no adept at dealing with bad nursing homes that good people don't talk. They've learned that it doesn't pay to make waves.

Shortly after The Record's series on the Bel Air Manors appeared, industry sources were saying that many nursing home owners were concerned that their facilities might be the next target of investigators.

Said one North Jersey administrator:

"We were very worried after Bel Air. Everyone thought they would be next. Everyone was like, 'Jeez us. Watch out, we heard they are sending an undercover investigator to your place.' So what could we do? We just clean up and fix up and make sure we have enough people working and hope for the best."

Fear can be a healthy motivator.

James Cunningham, lobbyist for the state's private nursing homes, agrees that such a plan could work. He said the good nursing homes, which make up the vast majority in New Jersey, have nothing to fear. "We'd all like to get rid of the bad apples," said Cunningham.

A few successful prosecutions could bring significant change. Employees would soon learn that contacting the strike force would bring swift results.

Such an aggressive enforcement system would create a new environment within a state's nursing-home industry, an environment where a bad operator would find it hard to survive.

One amateur nursing home investigator named Jo-Ann Wells understands the value of deterrence. She's had some experience as a leader in a housewives' crusade that got national TV exposure for a Pennsylvania nursing home on "60 Minutes."

Says Mrs. Wells:

"You wouldn't have to shut down too many, and absolutely drag those bastards, if you'll excuse my English, through the muck and the mire that they have dragged those old people, before the rest of them would get with the program."